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Exploring Colorectal Cancer Diagnosis Disclosure to First-Degree Relatives: An African American Family Case Series

Kamilah B. Thomas
University of South Florida

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Exploring Colorectal Cancer Diagnosis Disclosure to First-Degree Relatives:

An African American Family Case Series

by

Kamilah B. Thomas

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Community and Family Health
College of Public Health
University of South Florida

Co-Major Professor: Julie A. Baldwin, Ph.D.

Co-Major Professor: Carol Bryant, Ph.D.

Martha L. Coulter, Dr.P.H.

Clement K. Gwede, Ph.D.

H. Roy Kaplan, Ph.D.

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social support

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Dedication

I dedicate this Doctoral dissertation to my parents, Aldwyn and Claudette Thomas. There is no doubt in my mind that without their unconditional love, support, and encouragement, I would not have completed this great challenge.

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Table of Contents

List of Tables	iv
List of Figures	v
Abstract	vi
Chapter One: Introduction	1
Screening Recommendations	2
Need for the Study	4
Theoretical Basis of the Study	6
Social Support	6
Family Secrets	7
Purpose of the Study	8
Patient Research Questions	8
First-Degree Relatives Research Questions	9
Study Assumptions	9
Study Delimitations	9
Study Limitations	10
Definitions of Relevant Terms	10
Chapter Two: Review of the Literature	12
Health Disparities in the U.S. Defined	12
Psychosocial Factors and Health Disparities	13
Biology and Health Disparities	14
Race and Health Disparities	15
Health Disparities and Cancer	16
Colorectal Cancer and Health Disparities	16
Colorectal Cancer Screening Recommendations	17
Colorectal Cancer and Diagnosis Disclosure	19
Genetic Risk	19
Other Cancers	22
Family Secrets Framework	25
Social Support Framework	28
Summary	29
Chapter Three: Research Methods	31
Sample	33
St. Joseph's Hospital Cancer Institute	33
Advantages	34
Disadvantages	34

H. Lee Moffitt Cancer Center	35
Advantages	35
Disadvantages	36
Eligibility Criteria	36
Recruiting Participants	37
Patients	37
First-Degree Relatives	38
Token of Appreciation	38
Selection and Sample Size	38
Instrument	41
Face-to-Face and Telephone Interview Protocol	41
Data Management	44
Data Analysis	44
Use of Atlas.ti [®] Software	47
Patient and FDR Analysis	48
Family Group Comparison	48
Chapter Four: Results	50
Section I: Patients	52
Age, Marital Status, and Health Insurance	52
Social Economic Status	52
In-depth Interviews	56
Patient Individual Interview Findings	56
General Colorectal Cancer Diagnosis Experience	56
Disclosure Experience	58
Communication Context	61
Expectations and Reality of Disclosure	63
Effects of Disclosure	67
Current Perceptions of Colorectal Cancer	70
Section II: First-Degree Relatives	72
Age, Marital Status, and Health Insurance	72
Social Economic Status	72
Telephone Interviews	75
First-degree Relative Telephone Interview Findings	75
Disclosure Experience	75
Communication Context	78
Reaction to Disclosure	80
Impact of Disclosure	81
Current Perceptions of Colorectal Cancer	84
Section III: Family Group Comparison	84
Description of Family Groups	84
Family Group 1	84
Family Group 2	87
Family Group 3	89
Family Group 4	91
Family Group 5	94

Summary	98
Chapter Five: Discussion and Conclusions	100
Colorectal Cancer Disparities	100
Disclosure	102
FDR Screening	105
Spirituality	106
Contributions to Theory	106
Contributions to Public Health Practice	113
Strengths and Limitations	117
Recommendations for Future Research	120
Conclusions	121
References	123
Appendices	132
Appendix A: Concept Chart	133
Appendix B: IRB Approval Letters	134
Appendix C: Participant Recruitment Letters	137
Appendix D: Informed Consent Forms	140
Appendix E: Interview Guides	163
Appendix F: Thank You Note	167
About the author	End Page

List of Tables

Table 1	Research Questions & Theoretical Frameworks (Patient Version)	43
Table 2	Research Questions & Theoretical Frameworks (FDR Version)	44
Table 3	Sex, Age, Marital Status, & Health Insurance (Patients)	54
Table 4	Education, Employment & Annual Household Income (Patients)	55
Table 5	Sex, Age, Relationship, Marital Status & Health Insurance (FDRs)	73
Table 6	Education, Employment & Annual Household Income (FDRs)	74
Table 7	Family Group 1	86
Table 8	Family Group 2	88
Table 9	Family Group 3	90
Table 10	Family Group 4	92
Table 11	Family Group 5	95
Table 12	Evidence of Theory in Patient Responses	108
Table 13	Evidence of Theory in FDR Responses	112

List of Figures

Figure 1	Participant & FDR Enrollment	40
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Exploring Colorectal Cancer Diagnosis Disclosure to First-Degree Relatives:
An African American Family Case Series

Kamilah B. Thomas

Abstract

Colorectal cancer (CRC) is the second leading cancer killer in the United States and the third most common cancer in African American men and women. Though the overall death rates have declined, this reduction in mortality is smaller for African Americans than for Whites. Factors that are protective against colorectal cancer include occupational or recreational physical activity, a diet high in fruits and vegetables, and colorectal cancer screening with removal of polyps (polypectomy) before they progress to cancer. Compliance with CRC screening recommendations requires people to know if a first-degree relative (parent, sibling, and child) or second-degree relative (aunt, uncle, niece, nephew, and grandparent) has been diagnosed with colorectal cancer. Little is known about how patients disclose this information to their relatives and what type of information is disclosed when disclosure takes place. The role of the family has long been overlooked in research on African American health screening behavior despite the fact that family interventions have been known to produce favorable outcomes in diet, nutrition, and exercise. This qualitative study explored the disclosure process among African American colorectal cancer survivors and FDRs with whom they shared their diagnosis. Of special interest was the role of social support in the disclosure process and the criteria used to decide which relatives to tell. Findings from this study will be used to

advance the knowledge about the dynamics of CRC disclosure to first-degree relatives in African American families and ultimately increase CRC screening in relatives.

Chapter One

Introduction

The overall health of the United States (U.S.) population lags behind that of most industrialized nations due to the persistent and growing disparities in mortality, morbidity, and disability between Whites and people of color (Brulle & Pellow, 2006). African Americans bear a disproportionate burden of many health problems. Morbidity and mortality are higher among African American men than any other racial or ethnic group (Plowden & Miller, 2000).

Colorectal cancer (CRC) is of particular importance because it is the third leading cancer killer in the United States (American Cancer Society [ACS], 2009) and the third most common cancer in African American men and women (ACS, 2007). CRC is a disease in which malignant (cancer) cells form in the tissues of the colon or the rectum (National Cancer Institute [NCI], 2008). An estimated 7,120 deaths from CRC were expected to occur in 2009 among African Americans (ACS, 2009). The higher death rates account for one-fourth of the disparity in cancer death rates between African-American and white women and 11% of the disparity between African American and white men (ACS, 2007). Though the overall death rates have declined, this reduction in mortality is smaller for African Americans than for Whites. Chen et al. (1997) conducted a cancer survival study and found that blacks have a poorer colon cancer survival rate than white patients and have a more advanced stage of disease at diagnosis.

An estimated 16,440 cases of colorectal cancer occurred among African Americans in 2007 (ACS, 2007). Incidence rates among African American men and women are higher than those among whites (ACS, 2007). Though the exact causes of the disparity are unknown, there are several factors that increase the risk of colorectal cancer including obesity, physical inactivity, cigarette smoking, a diet high in red or processed meat, and heavy alcohol consumption (ACS, 2007, p. 10). Additionally, relatives of CRC patients have an increased risk of the disease with increasing strength of family history and younger age of diagnosis in relatives (ACS, 2007; NCI, 2008).

Improved preventive care may have an impact on narrowing the colon cancer incidence and survival gaps in the African American population. Factors that are protective against colorectal cancer include occupational or recreational physical activity, a diet high in fruits and vegetables, and colorectal cancer screening with removal of polyps (polypectomy) before they progress to cancer (ACS, 2009). Therefore it is important for African American men and women to engage in healthy behaviors that allow for prevention and early detection of colon cancer.

Screening Recommendations

An overview of the screening guidelines recommended by professional health organizations may provide further background on this important issue. The American Cancer Society, the American College of Radiology, and the U.S. Multi-Society Task force on Colorectal Cancer (a consortium representing the American College of Gastroenterology, the American Society of Gastrointestinal Endoscopy, the American Gastroenterological Association, and representation from the American College of Physicians) collaborated on updated consensus guidelines in March 2008 (ACS, 2008).

The new guidelines distinguish between screening tests that primarily detect cancer and those that are more likely to detect both cancer and adenomatous polyps (ACS, 2008). The updated guidelines recommend men and women at average risk for CRC to begin screening at age 50 using one of the following preferred tests to screen for polyps and cancer: 1) flexible sigmoidoscopy every 5 years, 2) colonoscopy every 10 years 3) double-contrast barium enema every 5 years, or 4) CT colonography (virtual colonoscopy) every 5 years (ACS, 2008; Levin et al., 2008). The USPSTF (2008) recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or colonoscopy in adults, beginning at age 50 years and continuing until age 75 years.

The following tests are primarily effective at detecting cancer alone because the opportunity for prevention is limited and not the primary goal: 1) fecal occult blood test (FOBT) annually, and 2) Stool DNA test which currently has an uncertain test time interval.

Screening at an earlier age is recommended for those who have a first-degree relative (FDR) with a history of colorectal cancer or polyps younger than 60 years of age, two FDRs of any age with a history of CRC, or a family history of familial adenomatous polyposis or hereditary non-polyposis colon cancer (Read & Kodner, 1999). The United States Preventive Services Task Force (USPSTF) has determined that the net benefits of screening is substantial for adults age 50 to 75 years (2008). However, updated USPSTF guidelines recommends against routine screening for colorectal cancer in adults ages 76-85 (USPSTF, 2008).

For people with increased risk, compliance with these screening recommendations requires people to know if a first-degree relative (parent, sibling, child) or second-degree relative (aunt, uncle, niece, nephew, and grandparent) has been diagnosed with colon cancer (Forrest et al., 2003). When people do not share information about cancer diagnosis or genetic testing information with relatives at risk, relatives are denied the possibility of taking appropriate preventive measures (Forrest et al., 2003). Research has found that most patients disclose genetic testing information to their first- degree and second-degree relatives (Hallowell et al., 2005). A general but central research question for this dissertation is what decision making criteria do patients use to help them decide to disclose or not disclose a cancer diagnosis with family members other than their spouse?

Need for the Study

For FDRs with increased CRC familial risk to adhere to the recommendation to be screened at an earlier age, knowledge of a first-degree relative's CRC diagnosis is important for determining the appropriate time to be screened. Research has found that most patients disclose genetic information to their first degree and second-degree relatives (Hallowell et al., 2005). Though research has provided information about which family members may receive genetic information, little is known about how patients disclose this information to their relatives and what type of information is disclosed when disclosure takes place (Hallowell et al., 2005). This is especially true for families in which men, rather than women, are at risk (Hallowell et al., 2005).

The role of the family has long been overlooked in research on African American health screening despite the fact that family interventions have been known to produce

favorable outcomes in diet, nutrition, and exercise (Salminen, Vahlberg, Ojanlatva, & Kivela, 2005). The social context of the family has an important and unique influence on individual and general practitioner consultation behavior (Cardol et al., 2007). In addition, the World Health Organization (WHO, 1976) has characterized the family as “the primary social agent in the promotion of health and well-being” (p. 17).

Given the important role of family influence on health behavior, health professionals may lean towards encouraging patients to disclose a CRC diagnosis to first-degree relatives. Research suggests that people refrain from disclosing sensitive information because of the need for self-protection or other protection (Afifi, Olsen, & Armstrong, 2005). For instance, if a family member reacts aggressively, individuals may refrain from revealing a secret for fear of judgment and ridicule, or fear the information may be used against them (self-protection) (Afifi, Olson, & Armstrong, 2005). In addition, individuals may fear that the disclosure will hurt the target of the disclosure, damage their relationship with that person, or impact other family members (other-protection) (Afifi et al., 2005). Therefore, it is important to understand the dynamics of disease disclosure from the patient’s perspective in order for health professionals to understand the pros and cons of disease disclosure and the effects of disclosure on the patient.

This study explored the disclosure process among African American colorectal cancer survivors and FDRs with whom they shared their diagnosis. Of special interest was 1) the role of social support in the disclosure process and 2) the criteria used to decide which relatives to tell. Findings from this study will be used to advance the lack of knowledge about the dynamics of CRC disclosure to first-degree relatives in African

Americans. The findings contribute to an understanding of the disclosure decision-making patterns among African Americans. Understanding the positive and negative impacts of CRC diagnosis disclosure among African Americans will lead to the identification of appropriate recommendations for disease disclosure to a first-degree relative. Additionally, an increased understanding of the criteria one uses to make a decision about CRC disclosure will contribute to the development of culturally relevant interventions that contribute to narrowing the CRC health disparity among African Americans.

Theoretical Basis of the Study

Social support. Social support has been identified as an important factor in cancer survivorship. A diagnosis of cancer affects the individual diagnosed as well as his/her family and others in his/her social network. Social support has been defined and measured in many different ways. Cobb (1976) defines social support as information from others that tells a person he or she is cared for, loved, esteemed, and part of a network of social obligations. According to House (1981) social support is the functional content of relationships which can be categorized along four basic types of support 1) Emotional support involves the provision of empathy, love, trust, and caring; 2) Instrumental support involves the provision of tangible aid and services that directly assist a person in need; 3) Informational support is the provision of advice, suggestions, and information that a person can use in addressing problems; 4) Appraisal support involves the provision of information that is useful for self-evaluation purposes, that is, constructive feedback, affirmation, and social comparison. Uchino (2004) notes that whereas many aspects of social support are defined separately in theory, these functions

of social support are associated with each other, and not easily divisible in daily life. Additionally, relationships that provide one type of support often also provide other types. Though the parts of social support are difficult to examine separately, the importance of social support for patients diagnosed with cancer warrants further research and was examined in this study. This is especially relevant when it comes to revealing private information such as a colorectal cancer diagnosis that may be deemed as a “family secret.”

Family secrets. Family secrets or private information within families can have important and relational consequences. The potential consequences that accompany the disclosure of a family secret make decisions about whether to reveal such information quite complex. According to Vangelisti, Caughlin, & Timmerman (2001), individuals who are thinking about whether to disclose information to a family member have many factors to consider. Vangelisti et al. (2001) reviewed criteria that individuals use to determine whether to reveal information deemed personal or intimate. It was found that people are most likely to reveal secrets when: 1) the secrets threaten their own well-being both physically and psychologically; 2) the anticipated response from a confidant is positive; 3) the communication context creates an opening or an opportunity for disclosure; 4) the impact of the disclosure on family members is positive such as receiving social support; and 5) when the disclosure itself brings some reward such as an empathetic response or social validation because the secret keeper has the ability to grant access to another.

Purpose of the Study

Given the importance of understanding CRC disease disclosure and the correct CRC screening intervals, this research examined the disclosure process among African American colorectal cancer patients. The specific research questions follow.

Patient Research Questions

Question 1: What factors influence patients' decisions to reveal a CRC diagnosis to family members?

Question 2: What decision-making criteria do patient's use to help them decide to disclose or not disclose a CRC diagnosis (including whether disclosure: a) threatens the patient's well-being; b) the anticipated response from a confidant is positive; c) the communication context creates an opening as in finding an opportunity for disclosure; d) the impact of the disclosure on family members is positive such as receiving social support; and e) when the disclosure itself brings some reward such as social validation)?

Question 3: What roles do emotional, instrumental, informational, and appraisal types of social support play in a patient's decision to disclose his/her diagnosis to an FDR?

First-degree Relative Research Questions

Question 4: How do FDRs perceive the information they received about the patient's diagnosis?

Question 5: How do diagnosed patients influence the screening behaviors of their FDRs through emotional support, instrumental support, informational support, and appraisal support?

Study Assumptions

1. The patients reported their experiences with CRC disclosure to the best of their knowledge/memory and did not falsify their recollections.
2. The FDRs reported their perceptions and the effects of learning about their family member's diagnosis to the best of their knowledge/memory and did not falsify their recollections.

Study Delimitations

The following delimitations were imposed on this study:

1. Results from the qualitative data by definition cannot be generalized to all African American colorectal cancer patients.
2. Colorectal cancer patients had to be at least 18 years of age.
3. Colorectal Cancer patients had to be six months to 4 years post treatment.
4. Colorectal cancer patients could not be going through active treatment at the time of the study.
5. Colorectal cancer patients had to have at least one living first-degree relative.
6. First-degree relatives (parent, sibling, or child) had to be at least 18 years of age.

7. First-degree relatives (parent, sibling, or child) could not have a personal history of colorectal cancer.

Study Limitations

The following are limitations of this study:

1. Patients and family members who participated in the interview may have been motivated to respond due to their positive or negative attitudes about disclosure.
2. Results of the study cannot be generalized to all patients with colorectal cancer or all family members of colorectal cancer patients.
3. Results from the study are based on self-reports, which are based on recall of events six months to five years in the past.

Definitions of Relevant Terms

African American: African American will be defined as those people who identify as being black and live in the United States. This may also include men and women who do not self-identify as being African American such as Afro-Caribbeans and Africans.

ATLAS.ti®: ATLAS.ti® is computer software used for the qualitative analysis of large bodies of textual, graphical, audio, and video data. It offers sophisticated tools to manage, extract, compare, explore, and reassemble meaningful segments of large amounts of data in flexible and creative, yet systematic ways. The program provides tools that let the user locate, code, and annotate findings in primary data material, to weigh and evaluate their importance, and to visualize complex relations between them.

Colorectal Cancer (CRC): Colorectal Cancer is a disease in which malignant (cancer) cells form in the tissues of the colon or the rectum (NCI, 2008).

Colorectal Cancer Treatment: Colorectal Cancer Treatment will be defined as primary surgery on the colorectal area with curative intent or any type of radiation or chemotherapy treatment.

Disclosure: Disclosure will be defined as sharing information about a CRC diagnosis with someone other than a healthcare professional.

First Degree Relative (FDR): First-degree relative will be defined as a biological parent, sibling, or child.

St. Joseph's Hospital Cancer Institute (SJHCI): St. Joseph's Hospital (SJH) is the largest hospital in the Tampa Bay area accredited by the American College of Surgeons. SJHCI provides advanced technology and cancer care (SJH, 2010).

H. Lee Moffitt Cancer Center and Research Institute (HLMCC): Moffitt Cancer Center and Research Institute is a National Cancer Institute (NCI) Comprehensive Cancer Center, located in Tampa, FL. Moffitt focuses on the development of early stage translational research aimed at the rapid translation of scientific discoveries to benefit patient care (H. Lee Moffitt Cancer Center & Research Institute [HLMCC], 2007).

Chapter Two

Literature Review

The following literature review will provide a historical overview of health disparities in the United States. Next, the impact of health disparities on cancer morbidity and mortality will be discussed with a focus on colorectal cancer and colorectal cancer screening rates and barriers. An overview of the theoretical frameworks that guided the study will be provided including if and how they have been used to address colorectal cancer in the past. Finally, the empirical evidence examining diagnosis disclosure is discussed, including an explanation of the gaps in the literature and a discussion on how this study attempted to address them.

Health Disparities in the U.S. Defined

The National Institutes of Health (NIH) defines health disparity as “the differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that exist among specific population groups in the United States” (2009). In 2000, United States Public Law 106-525, also known as the "Minority Health and Health Disparities Research and Education Act," provided a legal definition of health disparities:

A population is a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality or survival rates in the population as compared to the health status of the general population.

In the U.S., slavery was rationalized on the basis of racism, an ideology of oppression based on a belief in the inherent biological inferiority of one race and the superiority of another (Fiscella & Williams, 2004). The vestiges of slavery are revealed in the health status of African Americans in the U.S. given that biological or inherited differences associated with race make only a minor contribution to the disparate cancer burden among African Americans in the U.S. (ACS, 2007). Genetic variation within race is greater than between races (Freeman, 1998); however, life expectancy, morbidity, and mortality seem to place the burden of illness and disease on certain segments of the population.

Psychosocial Factors and Health Disparities

In 1990 the life expectancy at birth for the white population was seven years longer than for the black population. By 2007 the difference decreased to 4.6 years (National Center for Health Statistics [NCHS], 2009). Though the gap in life expectancy between the black and white populations has narrowed, disparity still exists. The overall mortality was 25% higher for black Americans than for white Americans in 2007 and the age-adjusted death rates for the black population exceeded those for the white population by 48% for stroke, 31% for heart disease, 21% for cancer, 113% for diabetes, and 786% for HIV disease (NCHS, 2009). These statistics provide the evidence that disparities in health exist.

Many of the causes of disparity point to socioeconomic differences. When socioeconomic factors are controlled, disparities diminish significantly and disappear altogether in some cases (Smedley, Stith, & Nelson, 2003). However, the majority of studies find that racial and ethnic disparities remain even after adjustment for

socioeconomic and other healthcare access-related factors (Smedley et al., 2003). “If one racial, ethnic or other population has a lower use rate even among the insured members of the group, it could be that other barriers to access including availability, overt or covert discrimination, care-seeking behaviors, or barriers that are difficult to measure, may be obstacles to care” (p. 6). In addition to access, health practices, psychosocial stress, and environmental exposures contribute to disparity. Given this reality, it is important to acknowledge that racial and ethnic disparities are found in many sectors of American life. African Americans, Hispanics, American Indians, and Pacific Islanders, and some Asian-American subgroups are disproportionately represented in lower socioeconomic ranks, in lower quality schools, and in poorer-paying jobs (Smedley et al., 2003).

Biology and Health Disparities

Many of the health disparities relate to disease that can be managed with adequate primary care and early detection. It is clear that biologic and phenotypic differences exist among the defined racial groups in the United States. Blacks suffer disproportionately from elevated blood pressure and cholesterol, as well as illnesses linked to coronary artery disease that can be treated with early intervention (Blanchard & Lurie, 2005). In addition, the combined death rate for all cancers in 2003 continued to be 35% higher in African American men and 18% higher in African American women than in white men and women (ACS, 2007). Though these statistics are clear, they track poorly with genetics (Brawley & Moore, 2006).

A closed society will conserve genetic traits within that society (Brawley & Moore, 2006). This is exemplified by populations in the U.S. that were segregated on the basis of race, ethnicity, economics, or other factors (Brawley & Moore, 2006). It has

been advised that the majority of genetic differences correlated or associated with race should be considered familial and not racial (Brawley & Moore, 2006) because race is not a biological construct, it a social construct that precisely captures the impacts of racism (Jones, 2000).

Race and Health Disparities

Many U.S. research studies document disparities in health status based on race. Race is a rough proxy for socioeconomic status, culture, and genes that captures the social classification of people in a race-conscious society as the U.S. (Jones, 2000). Jones (2000) offers a basic framework for understanding racism and its influence on health. According to Jones (2000), institutionalized racism comes in two forms: 1) material conditions and 2) access to power. “Examples of material conditions include access to quality education, sound housing, gainful employment, appropriate medical facilities, and a clean environment” (p. 1212). Examples of access to power include differential access to information (including one’s own history), resources (including wealth and organization infrastructure), and voice (including voting rights, representation in government, and control of media) (Jones, 2000).

Personally mediated racism is defined as “prejudice and discrimination where prejudice means differential assumptions about the abilities, motives, and intentions of others according to their race” (Jones, 2000, p. 300). Personally mediated racism can be intentional and unintentional and includes acts of commission such as surprise at competence and omission such as poor or no service. Internalized Racism is defined as “acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth” (Jones, 2000, p. 300). Not believing in others who look like

them, and not believing in themselves characterize it. According to Jones, institutionalized racism is the most fundamental of the three levels because once institutionalized racism is addressed, the other levels will cure themselves over time.

Health Disparities and Cancer

Racial differences have also been found in the quality and intensity of healthcare and diagnostic services for a broad range of procedures and disease areas even after adjusting for insurance status and severity of disease (Smedley et al., 2003). This is particularly important for cancer because it is best controlled by prevention through avoidance of exposures to cancer-causing agents and early detection (Brawley & Moore, 2006). Insurance status has emerged as a key predictor of the quality of care that patients receive and those with a private source of insurance generally receive a higher quality of care (Smedley et al., 2003). Racial and ethnic minorities are disproportionately represented in publicly funded sources or no health insurance at all (Smedley et al., 2003). Therefore, white Americans with cancer are more likely than black Americans to receive optimal screening, diagnosis, and optimal cancer treatment once diagnosed.

Colorectal Cancer and Health Disparities

Colorectal cancer is of particular importance because it is the third leading cause of cancer-related deaths in the U.S. (ACS, 2008) and the third leading cause of cancer deaths among African American men and women (ACS, 2008). An estimated 7,120 deaths from CRC occurred in 2007 among African Americans (ACS, 2009). The higher death rates account for one-fourth of the disparity in cancer death rates between African-American and white women and 11% of the disparity between African American and white men (ACS, 2007). Though overall death rates from CRC have declined since 1990,

the reduction has been smaller in African Americans than in Whites (0.9% per year versus 1.9%) (ACS, 2007). Chen et al. (1997) conducted a cancer survival study and found that blacks have a poorer colon cancer survival rate than white patients and have more advanced state disease at diagnosis. Though the exact causes of disparity are unknown, there are several factors that increase the risk of colorectal cancer including obesity, physical inactivity, cigarette smoking, a diet high in red or processed meat, and heavy alcohol consumption (ACS, 2007, p. 10).

Improved preventive care may have an impact in narrowing the colon cancer incidence and survival gaps in the African American population. CRC is a unique cancer in that screening for the disease offers the potential for primary and secondary prevention (Vernon, 1997). Factors that are protective against colorectal cancer include occupational or recreational physical activity, a diet high in fruits and vegetables, and colorectal cancer screening with removal of polyps (polypectomy) before they progress to cancer (ACS, 2007). Therefore it is important to develop culturally appropriate programs for African American men and women so that they can engage in healthy behaviors that allow for prevention and early detection of colon cancer. Programs such as these will contribute to the reduction of racial and ethnic health disparities in the United States.

Colorectal Cancer Screening Recommendations

The American Cancer Society, the American College of Radiology, and the U.S. Multi-Society Task force on Colorectal Cancer updated the CRC screening guidelines to distinguish between screening tests that primarily detect cancer and those that are more likely to detect both cancer and adenomatous polyps (ACS, 2008). The updated guidelines recommend men and women at average risk for CRC to begin screening at age

50 using one of the following preferred tests to screen for polyps and cancer: 1) flexible sigmoidoscopy every 5 years, 2) colonoscopy every 10 years 3) double-contrast barium enema every 5 years, or 4) CT colonography (virtual colonoscopy) every 5 years (ACS, American Cancer Society., 2008; Levin et al., 2008). The following tests are primarily effective at detecting cancer alone because the opportunity for prevention is limited and not the primary goal: 1) fecal occult blood test (FOBT) annually, and 2) Stool DNA test which currently has an uncertain test time interval.

Screening at an earlier age is recommended for those with a family history of CRC including those who have a first-degree relative (FDR) with a history of colorectal cancer or polyps younger than 60 years of age, two FDRs of any age with a history of CRC, or a family history of familial adenomatous polyposis or hereditary non-polyposis colon cancer (American Academy of Family Physician (Read & Kodner, 1999). Murff et al. (2008) found that African American FDRs were less likely to undergo colonoscopy screening compared to whites with affected relatives. Additionally, in a recent study by Rubin et al. (2009), of 253 CRC patients only 120 (47.4%) knew that their first degree relatives were at increased risk for the disease. Thirty-four point eight percent (34.8%) believed that their FDR had the same risk of CRC as the general population, and 14.2% believed that their FDRs were at a lower risk than the general population. Additionally, Caucasian patients were significantly more likely to know of their increased family risk than African-American patients. Rubin et al. (2009) also reported that it remains unclear what role the CRC patients play in the communication of risk to FDRs.

Colorectal Cancer and Diagnosis Disclosure

The literature on colorectal cancer diagnosis disclosure to first-degree relatives is sparse. However, there is analogous research that focuses on disclosure of other cancers and disclosure of genetic risk. These genetic risk studies are limited and mainly focus on late-onset disorders such as Huntington's disease, heredity breast/ovarian cancer, balanced translocations, and recessive disorders such as cystic fibrosis (Forrest et al., 2003; Julian-Reynier et al., 2000; Wagner Costalas et al., 2003). A few studies discuss breast and prostate cancer diagnosis disclosure as a part of a study, but the focus is not on the criteria individuals use to determine whether or not to reveal a diagnosis.

Genetic Risk

Wagner Costalas et al. (2003) describe the results from a survey designed to assess patterns of communication within families shortly after an individual receives results of BRCA1 and BRCA2 (BRCA1/2) gene mutation cancer status. The sample consisted of 162 women who received results from BRCA1/2 genetic testing. The authors were particularly interested whether there were difficulties in communicating the results and if the patient experienced distress with sharing the results. Using a telephone interview questionnaire with open-ended questioning, it was revealed that participants shared their results more often with their female relatives than with their male relatives.

Those with positive BRCA1 or BRCA2 genes shared their results with 82 (83.7%) of their relatives. Interestingly, when asked if there was a particular relative who seemed to have difficulty understanding the test results, respondents reported that 12.4% of their siblings had difficulties understanding the results compared with 1.54% of adult children (p.15). Gender was not statistically significant in that an approximately equal

percentage of male (8.3%) and female (7.4%) blood relatives were reported to have had difficulty understanding the test results (p.15) (Wagner Costalas et al., 2003).

The results of the Wagner Costalas et al. (2003) study revealed that individuals disclose their genetic test results to their at-risk relatives and they most often share their results with their adult sisters and daughters than with their adult brothers and sons (p. 15). This study did not delve further into the reasons why men were less likely to be told. These issues should be further explored because daughters of adult brothers and sons may be at risk for inheriting the gene for breast cancer and should be informed of that risk. Additionally, the difficulties experienced by the patients were not further explained in the study, indicating the need for further research in this area.

Julian-Reynier et al. (2000) conducted a cross-sectional self-administered survey, to determine women's attitudes towards the family disclosure of positive breast cancer genetic testing results and to determine the predictive factors of the diffusion patterns observed. The women in the sample attended a breast cancer genetic clinic in France. Of the 398 respondents, 383 had at least one living first-degree relative to inform. Only 8.6% of women attending cancer genetic clinics because of breast/ovarian cancer stated they would inform none of their living first-degree relatives. The sibling was the most frequently informed blood relative before children, mother, and father. Women in the family were also more informed than men.

Julian-Reynier et al. (2000) contend that family disease diagnosis disclosure of heredity disease areas is critical because informed patients are the key actors for disclosing genetic information to the relatives when a mutation has been identified in the family. However, the Julian-Reynier, et al. (2000) study does not further discuss the

impact disclosure may have on the patient or the stress that the disclosure process may pose on a patient.

The Wagner Costalas et al. (2003) and the Julian-Reynier et al. (2000) studies only involved women in their study populations due to the mostly female breast cancer patient population. It is imperative that disclosure in men also be explored. Hallowell et al. (2005) conducted in-depth interviews to explore the way in which information about BRCA1/2 testing is communicated within the families of men who undergo genetic testing. The sample included men (n=17), their partners (n=8) and adult children (n=4). They focused on cases in which the father had undergone BRCA1/2 predictive testing and described the process of communication within the immediate family. It was revealed that male patients and their partners perceive themselves as responsible for disclosing information about genetic testing and genetic risks to their children. The parents described three different communication strategies for their disclosure to their children: 1) complete openness, 2) limited disclosure, and 3) total secrecy. The adoption of the different strategies was influenced by children's competence and life stage and pragmatic considerations (such as if the delivery of the information was to be face-to-face). In families where cancer is currently an issue (relative recently diagnosed, treated or died) it may be easier for a parent to discuss and more difficult to hide from adult children (Hallowell et al., 2005).

None of the men in the Hallowell et al. (2005) study indicated that they did not want to inform their children of their cancer status, but some were unwilling to share information with their children until the test results were known. However, "lone parents may face difficulties when disclosing information about genetic testing to children and

may need additional support from genetic counselors/ clinicians and at-risk children may also require extra support” (Hallowell et al., 2005, p. 500). This study points to certain circumstances that may influence the ease or difficulty of disclosure. It is important to understand the impact of disclosure on those who have a risk based on heredity alone, not necessarily due to a gene mutation that predisposes them and their family members to an illness.

Other Cancers

Gray, Fitch, Phillips, Labrecque, and Fergus (2000) conducted separate and simultaneous interviews (three times) with Canadian men diagnosed with prostate cancer and their spouses who were referred by urologists in the Toronto area. Interviews consisted of open-ended questions designed to explore men’s decisions about a prostate cancer diagnosis disclosure and ongoing medical situations with others besides their spouse. Many men in the study commented that if it had been possible, they would have avoided telling anyone other than their spouse. The main criterion for men deciding whom to tell about their prostate cancer was their perception of the others’ right or need to know. Especially in the case of family members, there was often a felt sense of obligation to inform, expressed in terms of providing information about possible genetic risks for other family members. A few men in the study, especially those who were younger and employed, spread the news of their prostate cancer widely among friends and co-workers. They told men that they should pay attention to their health and get tested for prostate cancer.

The Gray et al. (2000) study provides important information about the decision-making criteria that men use in prostate cancer disclosure such as the others’ right or

need to know. It will be beneficial for future research to understand the social support factors that influence the disclosure, especially the characteristics and factors that influence those men who share their diagnosis widely with others.

A study by Henderson, Davidson, Pennebaker, Gatchel, and Baum (2002) documented and described disclosure patterns and attitudes among breast cancer patients. This study revealed some factors that may contribute to the degree to which breast cancer patients talk about their cancer. Though not true for all patients, most wanted to and were able to talk with others about their cancer. The degree of disclosure was predicted by the participant age in which younger subjects discussed their disease significantly more than older patients. Disclosure was also predicted by severity of disease, with more disclosure associated with greater severity of disease. Out of 270 participants, 20 reported little or no disease disclosure to anyone besides their spouse or doctor. Approximately one-third of the extremely low disclosers wanted to keep their cancer a secret, one-third found it difficult to discuss their cancer, and half wanted to talk to someone about their cancer. According to the authors, this suggests that some breast cancer patients have a desire for secrecy, while others may experience social constraints or barriers to discussion. Though this study contributes to the literature on cancer disclosure, it was a quantitative study and did not assess more subtle, qualitative aspects of disclosure (Henderson et al., 2002).

Hilton, Emslie, Hunt, Chapple, & Ziebland (2009) conducted a secondary analysis of narrative interviews of 37 young people between the ages of 18 and 34 at diagnosis to explore how they discussed their experience of disclosing their cancer diagnosis to families, friends, and wider social networks. They found that most men and women were open about their illness and told family, friends, and close colleagues. However, telling

loved ones about their diagnosis was one of the most difficult aspects of having cancer and patients delayed telling those they perceived to be vulnerable. Hilton et al. (2009) found that men made connections between disclosure and their identity in a way that women did not, and found that men were more secretive about their diagnosis. This study adds to the literature on disclosure among young adults with cancer and describes gender differences that impact disclosure. However, this study focused on multiple cancers and does not take into account the levels of stigma associated with different types of cancer that affect disclosure or the impact that familial risk has on disclosure.

Henderson et al. (2002) asserted that theoretical and empirical work suggests that inhibition of traumatic or stressful experiences is deleterious to health and well-being. Additionally Ballard-Reisch & Letner (2003) found that talking about cancer helps patients organize their thoughts and feelings and helps to make sense of their experience. However, Gray et al. (2000) found that there is no reason to suspect that it is psychologically or socially more adaptive to disclose to those in one's social network than not to disclose.

When it comes to disclosing to family members with a familial or genetic risk, it is widely assumed that informing persons about their genetic risk or susceptibility for cancer is beneficial (d'Agincourt-Canning, 2001). It is asserted that obtaining information may encourage identified individuals to engage in cancer screening or avoid exposure to behavioral risk factors such as poor eating habits or a sedentary lifestyle. However, these assumptions are based on a medical model that views the individual as rational, independent, and autonomous (d'Agincourt-Canning, 2001). In fact, in a study of 368 relatives of colorectal cancer patients, Madlensky, Esplen, Gallinger, McLaughlin, &

Goel (2003) found that perceived susceptibility to CRC, advice from family members, and exposure to public awareness information were not associated with screening. Murff et al. (2008) found that African Americans with multiple affected FDRs were half as likely to have undergone recommended screening procedures when compared to whites, even after adjusting for education, annual income, and insurance status. In both groups, the most common reason for not participating in screening procedures was lack of recommendation from their health care provider. This points to the need for further research to discover how African American FDRs perceive the information they receive when a family member discloses a CRC diagnosis and how this information impacts their health behaviors.

Therefore, additional research on how a patient rationalizes disclosure of diagnosis and the process of weighing the benefits and consequences will contribute to appropriate recommendations for patients. A growing area of literature known as “family secrets” has the potential to contribute to continued research in this area.

Family Secrets Framework

According to Brown-Smith (1998), “that which is kept secret or private has various meanings to different families and/or to different family members” (p. 24). Disease disclosure can be thought of as being a type of family secret. Little research has explored the criteria that people employ when they decide to reveal information deemed personal or intimate such as a disease diagnosis. There is a growing area of social work research that discusses the effects of secrets and disclosure within families. Revealing family secrets can have important personal and relational consequences (Vangelisti et al., 2001). Vangelisti et al. (2001) report that keeping family secrets is often portrayed as

having negative consequences for individuals and popular U.S. culture discourages family secrets. They contend that there is a broad spectrum of potential consequences that accompany the disclosure of family secrets which makes decisions about whether to reveal the secret complex.

Vangelisti et al. (2001) define criteria for revealing family secrets as the prerequisites or standards people use to judge whether they should divulge secret information about their family to others. The authors reviewed preliminary ideas about the criteria individuals may use when they consider whether to reveal a family secret. They found that people may reveal secrets when: 1) the secrets threaten their own well-being both physically and psychologically; 2) the anticipated response from a confidant is positive; 3) the communication context creates an opening or an opportunity for disclosure; 4) the impact of the disclosure on family members is positive such as receiving social support; and 5) when the disclosure itself brings some reward such as social validation.

A limitation of the definition of criteria for revealing family secrets proposed by Vangelisti et al. (2001) is that it is limited to secrets kept by the entire family from outsiders (whole family secrets). However, the findings point to the complexity involved in disclosing secrets. Additional research should be conducted in order to investigate if the criteria used are relevant to information about one's self kept from other family members and if the criteria is dependent on the type of secret, such as if the criteria is applicable to someone interested in disclosing a disease diagnosis to family members. The proposed study is innovative in that the Vangelisti et al. (2001) criteria have not been used to investigate a cancer diagnosis in general and a CRC diagnosis in particular.

However, the criteria for revealing family secrets are applicable to the current study because it will contextualize CRC disclosure as a secrecy issue in the literature.

Afifi et al. (2005) conducted a study with 171 families (629 family members) to determine the number and type of family members who were withholding secrets from one another. They used a quantitative survey and followed up with an in-depth interview. This questionnaire design was inappropriate because many questions were left unanswered because there was a lack of in-depth responses. The researchers found that individuals refrained from revealing secrets for fear of how their family member would respond, which was based upon aggressive reactions to prior revelations to this person. Conversely, the unpredictability of a reaction was also a factor. Communication efficacy played a role in that people continued to conceal negative secrets from aggressive family members whether or not they felt they had the ability to communicate the secret. If past experiences were consistently negative, individuals felt as though there was no way to communicate the secret in such a way that it could produce a positive response and they felt as if they had little or no ability to affect the interaction. Potential moderators included age, rigidity in a family member's values, time that a participant spent with their family members, and the longevity of the impact of the secret. The participants in this study were largely comprised of white, middle-class families and may not be representative of the diversity of families in the U.S. The current study will fill this gap by focusing on the African American family.

The Vangelisti et al. (2001) and Afifi et al. (2005) studies are specific to secrets about family relationships including secrets that go against cultural norms or those that would be considered immoral. In addition, the actual secrets of the participants were not

fully described in these studies making it difficult to generalize the results of these studies to a patient population who may want to reveal private information such as a colorectal cancer disease diagnosis.

Social Support Framework

Social support has been shown to be associated with increased cancer screening. However, these studies focused on general categories of support. Few studies have made finer distinction in the type of social support and providers of that support (Gili, Roca, Ferrer, Obrador, & Cabeza, 2006).

Gili, Roca, Ferrer, Obrador, & Cabeza (2006) used the concept of perceived social support to identify factors related to CRC screening adherence in a sample of siblings of CRC patients in Spain. The results found that adherents to CRC screening perceive a greater level of social support. However, this study did not examine the family as a source of support, only friends, work colleagues, and health staff.

Honda and Kagawa-Singer (2006) examined CRC screening adherence among a sample of Japanese Americans aged 50 and over. They found that emotional family support, but not the size of the networks, was indirectly related to adherence. However, this study was not focused on CRC patients or their family members who were at a higher risk for developing the disease.

Madlensky, Esplen, Gallinger, McLaughlin, & Goel (2003) examined relatives of CRC patients to determine whether decisions regarding CRC screening by relatives were influenced by social interactions with family members, friends, and physicians or public awareness campaigns. The quantitative study focused on advice giving and encouragement between at-risk relatives and their families, healthcare providers, and

social contact. Overall encouragement to be screened from family members was examined at the family level. The results indicated that screeners had more affected relatives, were more likely to discuss CRC screening after diagnosis in the family, and were more often encouraged by relatives than non-screeners. Though this study provided insight on the screening behaviors of FDRs, this study was based in Canada and did not include African Americans. In addition, the study did not include details on the type of encouragement or support from CRC patients that influenced FDR screening.

Kinney, Bloor, Martin, and Sandler (2005) examined the relationship between social networks and CRC screening among blacks and whites in North Carolina selected from a random sample in the general population. They examined relationships between both structural (number of ties and frequency of contact) and functional (emotional or instrumental support) aspects of social ties and utilization of colorectal cancer screening tests. They found that those who were most socially connected were more likely to report recent use of CRC screening. Neither emotional nor instrumental support was associated with screening behavior, suggesting that structural (number of ties and frequency of contact with ties) rather than functional (offering emotional or instrumental support) aspects of social ties may be important in influencing CRC screening behavior. This study points to the fact that these social support characteristics should be further explored using a qualitative methodology to determine if functional aspects of support are related to screening among FDRs of CRC survivors.

Summary

None of the studies reviewed thus far were focused on African Americans alone, or were specific to patients and FDRs. In fact, the majority of the studies were conducted

with populations outside of the United States (Forrest et al., 2003; Gray et al., 2000; Hallowell et al., 2005; Honda & Kagawa-Singer, 2006; Julian-Reynier et al., 2000). Therefore, research specific to colorectal cancer and African Americans should be further explored, taking into account the numerous social support and decision-making factors that impact CRC disclosure to family members who are at risk of developing the disease. This is important for developing appropriate recommendations and health promotion programs that result in reducing the CRC health disparity.

The current study will contribute to the literature by using a qualitative methodology to more fully examine the mechanisms of social support and criteria used during the CRC disclosure process. It will also examine disclosure from both the patient's and relative's perspective and focus exclusively on African Americans, the group with the highest rates of CRC in the U.S. The findings will contribute to an understanding of the disclosure decision-making patterns among African Americans and identify appropriate recommendations for disease disclosure to a first-degree relative. Ultimately, this study will contribute to the development of culturally relevant, interventions that contribute to narrowing the CRC health disparity among African Americans.

Chapter Three

Research Methods

The purpose of this study was to explore the role of perceived social support and the criteria for revealing family secrets on disease disclosure among African American male and female colorectal cancer survivors and their family members. This study used the social support and family secrets frameworks to examine how family support and closeness to the patient impact disclosure to first-degree relatives (FDR) and how this disclosure influences CRC screening activities in African American families. This exploratory study attempted to answer the research questions: 1) What factors influence patients' decisions to reveal a CRC diagnosis to family members?; 2) What decision-making criteria do patients use to help them decide to disclose or not disclose a CRC diagnosis (including whether disclosure: a) threatens the patient's well-being; b) the anticipated response from a confidant is positive; c) the communication context creates an opening as in finding an opportunity for disclosure; d) the impact of the disclosure on family members is positive such as receiving social support; and e) when the disclosure itself brings some reward such as social validation)?; 3) What roles do emotional, instrumental, informational, and appraisal types of social support play in a patient's decision to disclose his/her diagnosis to an FDR?; 4) How do FDRs perceive the information they received about the patient's diagnosis?; 5) How do diagnosed patients influence the screening behaviors of their FDRs through emotional support, instrumental support, informational support, and appraisal support?

This dissertation research study was a component in a larger study conducted at Moffitt Cancer Center (Principal Investigator: Dr. Clement K. Gwede; USF IRB #106449). The qualitative sub study instrument was administered prior to the instrument battery of the larger study. This two-phase study employed a qualitative research approach which included: 1) in-depth, face-to-face semi-structured, interviews with patients in phase one and 2) semi-structured telephone interviews with FDRs in the second phase (See concept model in Appendix A).

An in-depth interview is an open-ended, discovery-oriented method (Guion, 2001). The goal of the interview is to deeply explore the respondent's point of view, feelings and perspectives (Guion, 2001). This is appropriate when there is a need to understand individual decision-making (Guion, 2001). In this study, individual interviews were face-to-face and semi-structured: an initial set of questions were developed to guide the researcher and ensure key topics were covered in sufficient depth to answer the research questions, but the researcher changed the order, added questions, and probed for deeper meanings, as appropriate. Face-to-face interviews were used with patients in this study because they typically have the highest response rates and greatest face validity (Neuman, 2003).

Telephone interviews were conducted with FDRs of patients in this study. In a telephone interview, the interviewer calls a respondent at home, asks questions, and records answers (Neuman, 2003). The telephone interview is a popular method because ninety-five percent (95%) of the population can be reached by telephone (Neuman, 2003). The telephone interview is a flexible method with most of the strengths of face-to-face interview and it is half the cost (Neuman, 2003).

The participants for this study were patients diagnosed with and treated for colorectal cancer and their first degree relatives. Specific details regarding the participants, research design, data collection instruments, and procedures are presented in this chapter.

Sample

A two-phase sampling methodology was used for this study in order to reach the populations of interest. The primary sample frame was the cancer registry database at St. Joseph's Hospital located in Tampa, Florida. The secondary sample frame was the cancer registry database at Moffitt Cancer Center located in Tampa, FL. The secondary sample frame was employed to supplement the primary sample frame in order to recruit an adequate number of study participants.

St. Joseph's Hospital Cancer Institute

St. Joseph's Hospital (SJH) is affiliated with the H. Lee Moffitt Cancer Center and Research Institute (HLMCC), located in Tampa, Florida, which allows SJH to further expand its care so that patients are receiving the most up-to-date, advanced cancer care available as well as access to nationally-recognized clinical trials. The affiliation reinforces the concept of delivering primary cancer care in their highly regarded hospital while tapping the expertise and resources of academic researchers to assist in the treatment of rare and complicated cancers (SJH, 2010).

The comprehensive cancer registry at St. Joseph's Hospital's Cancer Institute (SJHCI) includes local and national data on individuals diagnosed with cancer. The Cancer Registry is an integral part of SJHCI and aids the institute in education, research, and lifetime patient follow up. The primary function of the Cancer Registry is to provide

continuum data management services under the leadership and support of the Cancer Committee. Cancer data collection is available to the medical staff for special studies, audits and research. SJHCI initiated data collection for the Cancer Registry in 1976 with over 40,000 accumulative cases. The registry reference year was changed to 1990 for better control of maintaining current follow-up and treatment on over 22,000 patients. Lifetime follow-up for former patients is a vital component of the cancer program. The registry utilizes the Electronic Registry System (ERS) for collection, analysis and quality improvement.

Advantages. When the study began, the researcher was a HLMCC employee. As such, the researcher had access to the patients in the SJHCI cancer registry. The cancer registry representative first gave the researcher permission to contact a patient to ensure that the patient met the minimum eligibility requirements. This affiliation with SJHCI gave the study more credibility among potential participants because his/her treating hospital recommended him/her for the study.

The procedures for obtaining patient contact information were simple, requiring contact with a cancer registry representative. As an HLMCC employee, the researcher had the ability to contact the cancer registry representative face-to-face or through other means and received a timely response.

Disadvantages. SJHCI has a significantly smaller amount of African American cancer patients compared to white patients. However, given the number of African American patients seen for colorectal cancer in 2005-2008, the sampling frame was determined to be suitable for this research study.

H. Lee Moffitt Cancer Center

The cancer registry database at the H. Lee Moffitt Cancer Center (HLMCC) includes over 80,000 analytic, non-analytic, historical, and autopsy cases accessioned since Moffitt began accepting patients in 1986 (HLMCC, 2007). The database includes all patients with active cancer and/or those receiving therapy for active cancer whose care is managed at HLMCC. Patients entered into the database are followed for life in order to determine treatment outcomes and survival (HLMCC, 2007). The HLMCC sample frame was determined to be appropriate because in 2006 alone, there were over 221 patients treated for colorectal cancer at the facility.

The Moffitt Cancer Registry follows guidelines set by the Florida Department of Health and the American College of Surgeons (ACOS) to determine patient eligibility for inclusion in the Cancer Registry database. Once the case-finding process is completed, and a patient is determined to be an eligible case, the patient's information is abstracted by a Certified Tumor Registrar (CTR). The Cancer Registry collects information on demographics, history of cancer, diagnosis, stage, treatment, recurrence, and survival (HLMCC, 2007). As a requirement of Florida statute 385.202, each patient admitted for the treatment of cancer is reported by HLMCC to the Florida Department of Health.

Advantages. At the time of the study, the researcher was a HLMCC employee. As such, the researcher had access to the patients in the registry and their treating physicians. When possible, the treating physicians recommended patients for the study. In this case, the physician recommendation gave the study more credibility among potential participants given that their treating physician recommended them for the study.

The procedures for obtaining patient contact information were simple, requiring contact with a cancer registry representative. As an HLMCC employee, the researcher had the ability to contact this person face-to-face or through other means and received a timely response.

Disadvantages. Historically, the racial and ethnic diversity of the patient population at the HLMCC has been limited, with the majority of patients being white. Though two patients were recruited from this sample, this sampling frame did not have an adequate number of African American patients to answer the research questions, and the majority of patients were recruited from the primary source described above.

Eligibility Criteria

The sampling plan represented a combination of the pre-determined variables and themes of interest: number of months/years since treatment and living FDRs. Eligible patients included male and female adults aged eighteen and older who had been treated with definitive surgery for localized or locally advanced CRC in the past five years. After obtaining names from the cancer registry based on the first level of eligibility, the following criteria had to be met: 1) patient received treatment with curative intent; 2) patient was six months to five years post initial definitive treatment; 3) patient had at least one living adult sibling or adult biological child, and 4) patient was not undergoing active treatment during enrollment. Those individuals outside of these guidelines were excluded from the study.

Eligible FDRs were those age 18 years and older, with no personal history of colorectal cancer.

Recruiting Participants

Patients. A list of potential patient participants including contact information was generated from the sampling frames described above. The director of the SJHCI sent an introductory letter to each potential participant using SJHCI letterhead. This letter explained that researchers from HLMCC would contact them about participating in a research study. Approximately two weeks later, the researcher sent a letter with specific details about study participation. Included in the letter was a telephone number for interested survivors to call for additional information and to enroll in the study. Those who did not call back to decline participation were contacted by the researcher to determine interest and potential eligibility. Those who declined to participate were not contacted again. The researcher documented participation rates including ineligibility and refusal for each potential participant by entering the information into a Microsoft Excel file stored on a secure database.

Potential participants were contacted by the means they indicated as preferred (physical mail, electronic mail, & telephone). During this contact, potential participants were screened for a second level of eligibility (information related to the date of last diagnosis and time of last treatment). The men and women who met the eligibility requirements and agreed to participate were contacted to schedule a date and time to participate in the in-depth face-to-face interviews at a community location of their choice (e.g., residence, library, local restaurant, bookstore etc.). Participants received a reminder phone call or letter prior to the scheduled interview time. Prior to participation in the study, participants were asked to provide informed consent for the study and gave

permission to take notes and record the interview. At the end of the interview the handwritten notes were used to validate responses.

First-degree relatives. As part of the eligibility criteria, patients recommended one or more first-degree relatives aged 18 and over to complete a telephone interview. Those relatives were contacted by telephone to determine eligibility. Those relatives who met the eligibility requirements and agreed to participate were scheduled for a telephone interview. Prior to the interview, the researcher mailed an informed consent document along with a self-addressed postage paid envelope that was to be signed and returned. If an informed consent document was not returned by the time of the scheduled telephone interview, the researcher obtained oral consent from the participant. This approach allowed for the flexible scheduling of the telephone interviews given that many FDRs preferred to schedule the interview prior to the researcher receiving the signed informed consent. Participants received a reminder phone call and letter sent through the U.S. mail prior to the interview.

Token of Appreciation

Patients and FDRs were given a \$30 money order to thank them for participating in the study. Once their signed informed consent document was received, a money order and a letter of appreciation were mailed to the participant.

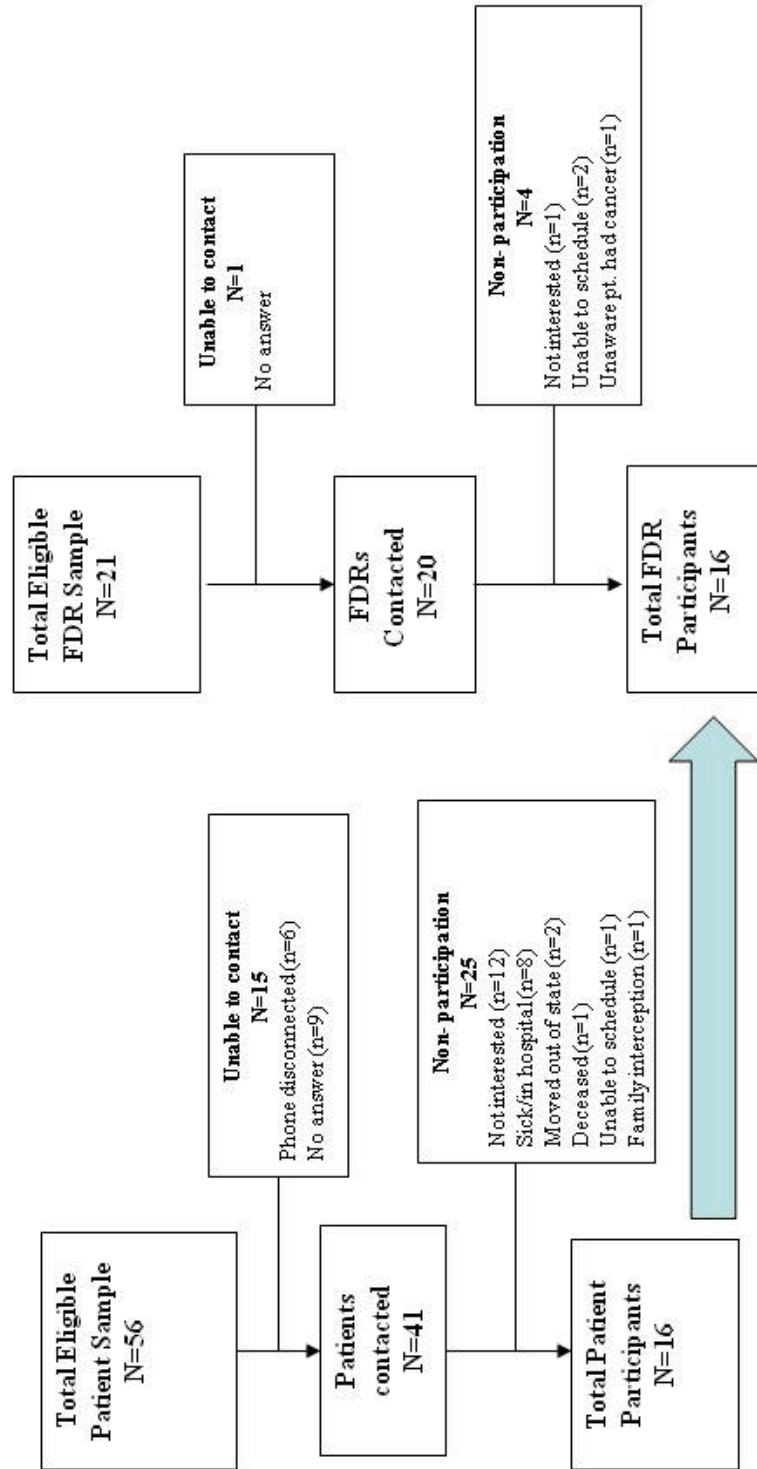
Selection and Sample Size

Sandelowski (1995) noted that a sample size of ten may be adequate for certain kinds of homogeneous or critical case sampling and Guest, Bunce, and Johnson (2006) proposed that a sample of twelve may be adequate. Qualitative research typically involves purposeful non-probability sampling aimed to develop a deep understanding

through information-rich cases (Sandelowski, 1995). Although not statistically representative, it is informationally representative in that data were obtained from persons who “have direct and personal knowledge of some event that they are able and willing to communicate to others” (Sandelowski, 1995, p. 180).

Using a purposive non-probability sampling strategy, the researcher conducted sixteen individual interviews with CRC patients (4 men and 12 women) who were six months to five years post-treatment for a response rate of 39%. Each patient was asked to refer one or more FDRs to complete a telephone interview. From this recruitment, sixteen FDRs (3 men and 13 women) completed telephone interviews for the study for a response rate of 80%. The total sample size for patients and FDRs in this study was 32 participants. Figure 1 shows total eligible and enrolled participants and their reasons for non-participation.

Figure 1: Patient & FDR Enrollment



Instrument

Face-to-face and telephone interview protocol. The investigator applied an adapted version of the social support and family secrets frameworks to structure the drafts of face-to-face and telephone interview guides. According to House (1981) social support is the functional content of relationships which can be categorized along four basic types of support 1) emotional support; 2) instrumental support; 3) informational support; and 4) appraisal support. According to the Vangelisti et al. (2001) family secret framework, people may reveal secrets when: 1) the secrets threaten their own well-being both physical and psychological; 2) the anticipated response from a confidant is positive; 3) the communication context creates an opening or an opportunity for disclosure; 4) the impact of the disclosure on family members is positive such as receiving social support; and 5) when the disclosure itself brings some reward such as social validation. Tables 1 and 2 show how constructs from each framework were used by the researcher to develop the questions used in the drafts of the interview guides.

In order to provide the evidence for the trustworthiness of the final instrument, a consensus process was employed to finalize the instrument drafts (Sandelowski, 1995). A panel of experts (investigator's dissertation committee) independently arranged all survey items developed by the investigator into theoretically sound categories. This sorting exercise aimed to ensure that each interview question clearly represented the intended theoretical construct. After consensus was reached, the final instruments were pre tested with four volunteers (one male and one female CRC patient and one male and one female FDR of a CRC patient). Participants involved in the pre testing were not enrolled in the

actual study and the information they provided was not analyzed for the results of this study.

Table 1: Research Questions & Theoretical Frameworks (Patient version)

Instrument Question	Theoretical Framework	Construct	Research Question
1) Can you think back to when you were first diagnosed and tell me about your experience?			1
2) Who did you decide to tell about your diagnosis?			
3) Within your immediate family, which relative did you decide to tell? (make list)			
4) What was the decision like for you? (Probe: What was hard, easy? What factors did you consider [family secrets general]?)	Family Secrets	Secret threatens well-being; Anticipated response positive; Communication Context; Impact Positive; Disclosure brings reward	1,2
5) How did you expect people to respond? What did you hope would happen [impact positive, disclosure brings reward]? (Probe: Did you want them to show that they loved you, cared for you, in what way [emotional support]? Did you hope they would take you to appointments, help you cook or clean [instrumental support]? Did you want them to find out more about CRC or get more information for you [informational support]? Did you want them to tell you that you were handling the news of your illness well or that it wasn't your fault [appraisal support]?)	Family Secrets; Social Support	Secret threatens well-being; Anticipated response positive; Communication Context; Impact Positive; Disclosure brings reward Emotional support; Instrumental support; Informational support; Appraisal support	1,2,3
6) What was the major reason you decided to tell ____ [family secrets; social support]? How did it go when you told him/her?	Family Secrets; Social Support	Secret threatens well-being; Anticipated response positive; Communication Context; Impact Positive; Disclosure brings reward	1,2
7) Think back to when you revealed your diagnosis, when did you feel it was an appropriate time to reveal your diagnosis [communication context]? What type of setting or environment was helpful? (Probe: Were you at home[communication context]? Was it over the phone[communication context]? Was it quiet [communication context]?)	Family Secrets	Communication context creates an opportunity for disclosure	1
8) How did you feel?			
9) How did they respond? What did she/he say? What did she/he do?			
10) Was this how you expected them to respond? How was it different? [disclosure brings reward; impact of disclosure positive; social support general]	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	3
	Family Secrets; Social Support	Impact Positive; Disclosure brings reward; Emotional support; Instrumental support; Informational support; Appraisal support	1,2,3
11) How do you feel now about your decision to share your diagnosis with him/her? (Probe: Are you glad/ sorry that you shared it with them? Why [anticipated response positive; well being threatened; social support]?)	Family Secrets; Social Support	Anticipated response positive; Secret threatens well-being; General social support	1,2,3
12) What made you not tell those relatives [anticipated response, communication context, impact of disclosure, reward]?	Family Secrets	Secret threatens well-being; Anticipated response positive; Communication Context; Impact Positive; Disclosure brings reward	1,2
13) Do you wish you had told them? Why do you say that?	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	3
14) As you think back about all of the experiences that we have discussed today, how do you think disclosing this type of information impacts relatives? (Probe: What about their decisions to get screened [informational support]? Do you know if any of your relatives got screened after you told them? (Probe: Who? What did they tell you about their decision to be screened [social support]?)	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	3

Research question key: 1) What factors influence a patient's decision to reveal a CRC diagnosis to family members?; 2) What decision making criteria do patient's use to help them decide to disclose or not disclose?; 3) What roles do emotional, instrumental, informational, and appraisal types of social support play in a patient's decision to disclose their diagnosis to an FDR?

Table 2: Research questions & theoretical frameworks (FDR version)

Instrument Question	Theoretical Framework	Construct	Research Question
1. Can you tell me about when you first learned that _____ had cancer?			
2. Who told you that she/he had cancer?			
3. How did you react? (Probe: Were you empathetic [emotional support]? Did you offer to do anything to help (like cooking, cleaning) [instrumental support]? Did you offer advice [informational support]? Did you tell them that they handling the news of cancer in a good way [appraisal support]?)	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	4
4. What did you feel?			4
5. What impact did this news have on you? Did you do anything differently?	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	4
6. Why do you think s/he told you? (Probe: Did they worry about survival or recovery [secret threatens well-being]? Was the news too stressful not to share [secret threatens well-being]? Was the environment good for that type of conversation [communication context]?)	Family Secrets	Secret threatens well-being; Anticipated response positive; Communication Context; Impact Positive; Disclosure brings reward	4
7. What do you think your family member expected from you by telling you about their diagnosis [social support general; impact positive; disclosure brings reward]?	Social Support; Family Secrets	Emotional support; Instrumental support; Informational support; Appraisal support; Impact Positive; Disclosure brings reward	4
8. Have you personally been screened for CRC? Was that before or after learning about your family member's diagnosis [informational support]?	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support; Impact Positive	5
9. What impact did the diagnosed patient have on your decision (or not) to get screened [social support general]?	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	5
10. Did they do anything to encourage you to be screened? (Possible probes: Did they care if you were screened [emotional support]? Did they give you information on where to get screened [informational support]? Did they offer to take you to get screened [instrumental support]? Did they make you feel good about being screened [appraisal support]?)	Social Support	Emotional support; Instrumental support; Informational support; Appraisal support	5

Research question key: 4) How do FDRs perceive the information they received about the patient's diagnosis? 5) How do diagnosed patients influence the screening behaviors of their FDRs through emotional support, instrumental support, informational support, and appraisal support?

The guides were developed based on a literature review of previous studies on disease diagnosis disclosure and with studies that incorporated social support and family secret frameworks, as well as the expertise of advisors and mentors. Based on data from the pilot test and additional feedback from advisors and mentors, the qualitative interview guides were revised and modified. See Appendix B for final interview guides.

The semi-structured in-depth face-to-face interviews with patients lasted 20-30 minutes and the semi-structured telephone interviews with FDRs lasted 15-30 minutes.

Data Management

Data were collected using in-depth, in person interviews with a semi-structured interview protocol. The interviews were recorded using a digital voice recorder that was saved as an audio file. To ensure accurate recordings of the participant's responses, all equipment was tested immediately before each interview. Back-up equipment was also present at each interview. The saved audio file was sent to a professional transcriber in order to prepare the written transcripts. All data were stored in the researcher's password secured computer and locked file cabinets. Only personnel working with the study had access to the computer and file cabinets and all persons working with the study were required to sign confidentiality statements. Informed consent forms were also stored in a locked file cabinet, in a separate file, away from interview transcripts.

Data Analysis

The final verbatim transcriptions were formatted into an electronic Microsoft Word® document. Interview transcripts were analyzed using Atlas.ti® software. Once an interview was completed, the electronic data file was sent to a professional transcriber for transcription. The data analysis began as soon as the transcripts were returned to the

researcher. The researcher employed the constant comparative method of qualitative analysis developed by Glaser (1965). This method consisted of: 1) comparing cases applicable to each content category, 2) integrating categories, and 3) delimiting the theory.

The researcher reviewed the data and developed a priori codes that were specific and tied to the research questions and theoretical framework. While coding a case for a category, the researcher compared it with the previous cases coded in the same category (Glaser, 1965). For example, as the researcher coded a case in which a patient expected instrumental support from an FDR, she then compared this case with other cases previously coded in the same category before further coding (Glaser, 1965). The constant comparison of the interview text provided common themes regarding disease disclosure to first-degree relatives based on the individual various types of social support and the criteria used to reveal secrets. During this process, a codebook was developed to operationalize and define each of the themes.

After review of the first set of common themes and the development of the initial codebook, the researcher employed a double coding method to be used for the final two steps of the constant comparative method. Half of the patient transcripts and half of the FDR transcripts were randomly selected to be coded by a second coder. The second coder for the patient transcripts holds a Master of Public Health degree and is a former research assistant for the parent study. The second coder for the FDR transcripts holds a Master of Public Health degree and is a current doctoral student at a college of public health. Both coders are experienced in qualitative research coding.

The main focus of the axial coding was to examine the initial codes and determine the

causes and consequences, strategies and process that cluster together while identifying sub-themes (Neuman, 2003). This process helped the researcher determine which themes to discard and which themes to examine further (Neuman, 2003). The secondary coders assisted with this process. During this process, the codebook was revised in order to update the code categories from the first open coding pass. The dialogue between the researcher and second coder helped to inform the revised codebook. This was especially useful in areas where the codes were initially too broad. For example, an initial code of “informational support” was refined into the sub-code of “informational support for familial risk.”

Finally, delimiting the theory, also known as selective coding was used as the final coding step. As the theory developed, this step reduced the data findings. Using the updated codebook, the researcher and secondary coders looked selectively for cases that illustrated themes and made comparisons and contrasts after all of the data collection was complete (Neuman, 2003). This allowed for coding according to the boundaries of the researcher’s theory (Glaser, 1965).

Use of Atlas.ti[®] Software

Data management and analysis were supported by the use of Atlas.ti v6, qualitative data analysis software. Creswell (2007) describes Atlas.ti as a PC, Windows-based program that enables researchers to organize their text, graphic, audio, and visual data files into a project file called a Hermeneutic Unit (HU). An HU can also be used to organize coding, memos, and findings associated with these files. In addition, Atlas.ti also has search features and query tools that allow the researcher to rapidly search, retrieve, and browse all data segments and notes relevant to an idea (Creswell, 2007).

Patient and FDR Analysis. For this study, two HUs were created: one HU was created for patients and the other for first-degree relatives. The codebook and transcripts were uploaded to their corresponding Atlas.ti HUs in order to manage and organize the data. After the hand-coding of each transcript was complete and agreement was reached between the researcher and secondary coders, all coders were responsible for inserting their information into their respective HU. In order to do this, Atlas.ti was used to select sections in the transcript text and assign codes via a code list comprised of the previously uploaded codebook. After this process was complete, an output file was created from each individual HU. These outputs contained the quotations and codes for each participant and can be exported to SPSS, HTML, XML, and CSV. The outputs can also be saved as printable RTF files that can be opened with Microsoft Word. These outputs were analyzed to complete the patient and FDR results section.

Family Group Comparison. In order to compare the responses of the patients with two or more family members who participated, the Family Manager Tool within Atlas.ti was used. The Family Manager allows the researcher to categorize each transcript into groups based on the intentions of the analysis. For this study, the Family Manager was used in the first-degree relative HU to place relatives of a given patient together. For example, the patient with the ID ‘PAT 555’ has two relatives – a sister (FDR 556) and a son (FDR 557). The two relatives were placed in the same group given the label ‘PAT 555.’ The researcher is then able to export a file that contains the quotations for a given family organized by participant ID and codes. The Family Manager Tool was not used in the patient HU. Instead, a file for each patient containing both codes and quotations was exported and printed discretely. This enabled the

researcher to compare each patient output juxtaposed to its corresponding first-degree relative output containing both codes and quotations for all first-degree relatives within that family. These two outputs were analyzed and used to complete the family group comparison in the results section.

Chapter Four

Results

This chapter presents the results of the data analysis. As explained in Chapters I and II, the Family Secrets Framework and the Social Support Framework serve as the guiding theoretical frameworks to understand the information collected in the study. The analysis was conducted with the goal of answering the research questions for this study:

- 1) What factors influence patients' decisions to reveal a CRC diagnosis to family members?
- 2) What decision-making criteria do patients use to help them decide to disclose or not disclose a CRC diagnosis; including a) whether disclosure threatens the patient's well-being; b) the anticipated response from a confidant is positive; c) the communication context creates an opening as in finding an opportunity for disclosure; d) the impact of the disclosure on family members is positive such as receiving social support; e) when the disclosure itself brings some reward such as social validation.
- 3) What roles do emotional, instrumental, informational, and appraisal types of social support play in a patient's decision to disclose his/her diagnosis to an FDR?
- 4) How do FDRs perceive the information they received about the patient's diagnosis?

5) How do diagnosed patients influence the screening behaviors of their FDRs through emotional support, instrumental support, informational support, and appraisal support?

Data was obtained through face-to-face semi-structured in-depth interviews with patients, and telephone interviews with first-degree relatives. Transcripts of the interviews were analyzed in two ways: first by emerging themes that became evident by topic area and second by the theoretical frameworks used to inform the design of the study. Data were analyzed using the ATLAS.ti 6.0 software. In addition to themes that emerged from the analyses, quotations are provided to illustrate the perspective of the interviewed participant.

The results are presented in three sections. Section I describes the patient sample and reports the qualitative results from the patient interviews. Section II describes the first-degree relative sample and reports the qualitative results of the first-degree relative interviews. Section III is an analysis of the five families in the study (those patients who had two or more family members who participated in the study). This analysis is a side-by-side comparison of the patient responses and the related FDR questions. A summary of key findings concludes the chapter.

Section I: Patients

Age, marital status, and health insurance. The patient sample consisted of 16 adults: 4 men and 12 women who were diagnosed with colorectal cancer within the past 5 years (2004-2009). Ages of the participants in the total patient sample ranged from 27-80 years, with a mean age of 63 and a median age of 64. With regard to marital status, approximately 50% of the total sample reported being married, 12.5% were divorced, 25% were widowed, 6.3% were separated and another 6.3% had never been married (See Table 3).

Approximately 87.5% of participants indicated they had health insurance, with 12.5% indicating they had none. More than half (56.3%) reported participation in the Medicare program, 31.3% had private health insurance.

Social economic status. In examining the social economic status (SES) of the patient participants, including education, employment status, and annual household income, the majority of the participants had at least a high school education (Table 4). One person preferred not to answer the question about education, four of the participants were college graduates, two had some college or technical school, five were high school graduates, two completed some high school, and another two completed some elementary school. Half of the patients were retired, five were employed for wages, one was out of work for more than one year, another person was out of work for less than one year, and one was unable to work.

Participants' annual household income ranged from less than \$10,000 per year to greater than 100,000. Four participants reported incomes of less than \$10,000, five reported making \$10,000-\$25,000, two reported incomes of \$25,001-\$35,000, one

indicated an annual income of \$35,001-\$50,000, two reported incomes of \$50,001-\$75,000, and one participant reported making over \$100,000. One participant preferred not to answer the question about income.

Table 3: Sex, Age Marital Status, and Health Insurance (Patients)
(N=16)

Variable		N	%
Sex	Male	4	25
	Female	12	75
Age	20-29	1	6.3
	30-39	0	0
	40-49	1	6.3
	50-59	4	25
	60-69	5	31.3
	70-79	3	18.8
	80-89	2	12.5
Marital Status	Married	8	50
	Divorced	2	12.5
	Widowed	4	25
	Separated	1	6.3
	Never married	1	6.3
Health Insurance	Yes	14	87.5
	No	2	12.5
Health Insurance Type	Medicare	9	56.3
	Private	5	31.3
	N/A	2	12.5

Table 4: Education, Employment Status, & Annual Household Income (Patients)
(N=16)

Variable	N	%
Education Completed		
Elementary school	2	12.5
Some high school	2	12.5
High school graduate	5	31.2
Some college or tech school	2	12.5
College graduate	4	25
Prefer not to answer	1	6.3
Employment Status		
Employed for wages	5	31.3
Out of work for more than one year	1	6.3
Out of work for less than one year	1	6.3
Retired	8	50
Unable to Work	1	6.3
Annual Household Income		
Less than \$10,000	4	25
\$10,000-\$25,000	5	31.3
\$25,001-\$35,000	2	12.5
\$35,001-\$50,000	1	6.3
\$50,001-\$75,000	2	12.5
\$100,001 or more	1	6.3
Prefer not to answer	1	6.3

In-Depth Interviews

Semi-structured in-depth interviews were conducted from May 2009-August 2009. The interviews were conducted with the use of an interview guide, which included a list of questions grouped by topic and domain. Interviews were conducted with a preformulated interview guide, but answers to those questions were allowed to be fully expanded at the discretion of the interviewer and interviewee, and could be enhanced by probes.

All sixteen of the interviews were completed face-to-face. Fourteen were conducted at the homes of the patients, one was conducted at a local restaurant, and one was conducted at a local hospital. Each interview lasted approximately 20-30 minutes.

Patient Individual Interview Findings

General colorectal cancer diagnosis experience. The first part of the interview focused on the patient's experience with learning of his/her diagnosis. In answer to the first question, "Can you think back to when you were first diagnosed with Colorectal Cancer and tell me about your experience," most participants answered in the context of when they first experienced symptoms that caused them to seek medical attention.

Examples of the responses are below:

Well I guess I was a bit prepared for the diagnosis because I started having, I went to the doctor with symptoms and I had been online, just kind of looking up the symptoms, so there was kind of red flags all over the place in terms of you know what those symptoms occurring, you that if it's cancer that was said to me in advance. (51 year old woman)

I was telling her one day that when I drank water, you know my stomach hurt. She said well, why don't you go have a colonoscopy done? So I'm thinking okay, well this ain't going to hurt anything. (59 year old male)

So in the beginning, I saw when I cleaned myself and I saw the blood, of course I panicked, of course, and called Dr. XXX right away. I had constipation

constantly, you know but that was the first time I'd seen the blood, so then I said "Uh-oh, that's not good! (89 year old female)

Experiences of faith and spirituality were present among other participants and were included as a major part of their diagnosis experience:

So I struggled and prayed, and struggled and prayed. (54 year old female)

The only thing I can do myself is pray, and hope for the Lord's favor, because he is a good God. He will take care of you. (63 year old female)

...my daughter is a strong believer also, so she was telling my husband that, "Don't worry, God has this all in his hands." And you know, and they prayed about it, and we prayed about it, and one of my daughter's boyfriends, he prayed. He's a minister. He prayed. He came in the hospital and prayed with us, and we read scriptures, and the normal stuff. (65 year old female)

The next question asked the patient, "What were the first three things that came to mind when you first learned about your diagnosis?" The majority of patients focused on one major thing that came to mind. Two patients talked about the children that were in their care and about making provisions for them before beginning treatment. Another patient was worried about whether the cancer had spread. The topics of death and dying were mentioned quite frequently. Some patient thoughts included:

I did cry, real hard, and I wanted to go home right then because I said if I'm going to die, I want to die at home where my husband died at. (54 year old female)

The first thing come to my mind, tell the doctor to go out of the room so I can deal with my oncoming death. (48 year old female)

But, you know, that was my worst day, and all the day long all I could think of was, you know, I'm not going to see my kids have children, you know, I'm not going to live, all the negative stuff. (54 year old female)

In addition to the topic of death, patients expressed a strong desire to pray and to use their faith and spirituality to deal with the challenging road ahead. Patients did not mention religion or a belief in a particular denomination of Christianity. Though some

patients referred to a pastor, most expressions of faith and spirituality were general and focused on having a relationship with a higher power.

It kind of upset me a little bit, but I learned to pray, to deal with it, and I talked to my pastor and my pastor kept coming out there praying for me. (54 year old female)

First, pray. Prayer came to my mind immediately at a Stage 4. In fact, even before Stage 4, prayer came to my mind every day of my life. (48 year old female)

So I just started talking to the Lord and after that really, I really didn't have time for anything to come to mind... (64 year old female)

Disclosure experience. After allowing the patients to get comfortable talking about their diagnosis experience, the next part of the interview focused on the patients' experiences with disclosing their colorectal diagnosis with their family members. Patients were asked which first-degree relatives they decided to tell, the reason for telling, and the results of telling. Patients reported that they disclosed their diagnosis to their spouses and a range of FDRs including parents, children, and siblings. Many also told second-degree relatives (including aunts, uncles, nieces, nephews, and cousins) along with co-workers and friends. A few patients were unable to tell family members prior to surgery, due to the lack of a definitive diagnosis until surgery. In these cases, the family members found out about the diagnosis at the same time as the patient:

We all found out exactly about the colorectal cancer together from the doctor when they did the surgery. (80 year old female)

When they admitted me, my other daughter came to see what was going on with me, and that's when he (the physician) got a chance to talk to her. (65 year old female)

Because, when I found out myself and I was talking with my husband and the doctors, we asked a lot of questions, and some of my children were there, my daughters were there. (60 year old female)

There was not a patient interviewed who indicated that he/she did not inform at least one family member about their colorectal cancer diagnosis. However, two patients admitted that they delayed telling certain family members:

Yeah, my daughter, my son, my husband, my sons that's here because I have a lot out of town and all over the world... I didn't tell all of them right away because it wasn't time, and I wasn't in no position. (65 year old female)

I really didn't discuss it with him until I went to see my oncologist, you know Dr. XXX, the surgeon, to really know what was what. And I really didn't know nothing until I actually had the surgery and they did the biopsy to see that it spread... And then that's when I really got into details and told my mom, my family. (63 year old female)

Patient responses to the question, "What was the decision of who to tell like for you?" focused on the ease or difficulty associated with disclosing the news to family members. Eleven (n=11) said that it was easy to disclose and three (n=3) admitted that it was difficult to disclose. The other two patients said that one particular family member told the others on their behalf and there was no need to personally disclose to any other family member.

Some of the reasons patients had for saying that it was easy to disclose are reported below:

No, no. It wasn't hard, no. I guess it would have been if she had not been a doctor, you know. (89 year old female)

No, it wasn't hard. I just spoke out, told them what was going on and everything. (70 year old male)

It was pretty easy. I told them. Well, if I died they knew, if I lived, then they understand me. (60 year old female)

For some patients, the decision to tell was described as difficult; however, patients felt that it was important to tell family members because they needed to know:

Yeah, so it was very-that was very overwhelming, and then having to try to communicate, like I talked to my mother, you know, just trying to communicate the, you know, the extent of what they are saying, and you know, so that's when it really got scary for me... (51 year old female)

Well, it wasn't easy for me to tell. I just did it. You know, it's just something that had to be done, you know. (54 year old female)

Well, I feel like if you've got children, no matter what the situation is, they need to know. You know, that's something you don't hold back, you know. So, I went over and told them, so they was, you know. (48 year old female)

Other patients considered the potential negative consequences of not disclosing as a reason for telling family members about their diagnosis:

Because they going to find out anyway. If I don't tell them, and I go down, they still going to find out...But if you lie, then I've got to go all back over this thing, and straighten it out and all. (76 year old male)

Let them know because you don't know, maybe you wait a little bit too late and you know someone might not be taking it good, so you just wind up getting lost if you don't do it. (75 year old female)

Besides telling family members because they were in frequent contact with them, most patients said that the major reason for disclosure was to make their first-degree relatives aware of the FDRs' risk for the disease:

You cannot hide it from them, and if the truth of the history, now I'm the first one with a colorectal history in my family. If you hide it from them, it is not part of the success plan in the future; it is a part of your family now. And you want to be able to watch out for it, you want that memory to be at my mother's age, in her forties, she was diagnosed with a stage 4 colorectal cancer, so that if there is any symptoms in the future, whether they think it's just a little pain, and even on their birthday, early detection is a way that I teach those children. (48 year old female)

Because I wanted them to get tested and wanted to make sure that everybody in the family, you know, know whether it's cancer in the family because my father died of cancer about ten years ago, and so I wanted everybody to get tested and everybody to take care of their own selves on that side because my father passed from cancer. (66 year old male)

...because one of the things that I stumbled across while I was researching online was some statistics on African Americans and the fact that they tend to present

well advanced, and so some of the recommendations were even African Americans are screened, you know, up to ten years earlier than 50, and so I wasn't 50 at the time, and so, and I was reading where your siblings, everything, need to be screened within 10 years of your age that you were diagnosed... (51 year old female)

In response to the question, "How did it go when you told him/her?" patients said they considered their family members' feelings and minimized the seriousness of colorectal cancer as much as possible in an attempt to reduce the family members' concern.

So that wasn't-so then, when I did go, I did find out, and I said, "Dr. XXX said he thinks he saw something there and we've got to take care of it right away," you know and so, you know I tried to put it as easy as if it's no big deal, you know. (89 year old female)

Well, just in case if I died or something, you know they would know what I died with, you know. That if I had to take treatment, they would know that I had to take treatments, so they would understand, I don't want them worrying about it. (60 year old female)

But it was important to tell them as soon as the anger, the first couple of days, was set into reality. It was important to draw them near and tell them, "It's serious. But we're okay... I decided to minimize cancer word from the beginning. (48 year old female)

Communication context. The next part of the interview attempted to understand the communication context of the disclosure. The patients were asked to describe when they felt it was an appropriate time to reveal their diagnosis and the setting of the disclosure. This was done to understand when the patients felt there was an appropriate opportunity for disclosure. Five (n=5) patients told their family members about their diagnosis over the telephone. Ten (n=10) patients told family members face-to-face. One patient said that she told some family members face-to-face and others over the phone. Some responses from those who told their relatives over the telephone are below:

I gave a call to my daughter and she lives in Dallas, and I told her what he had found. (89 year old female)

Just me and my brother. Yeah, I told him about it. I told him I said well, when I found out about it I just called and told him. I said you know, I got cancer, I've got to have an operation. (59 year old male)

I think I called my mom that, later that, yeah, I think I called her, because she was working. I think I called her later on in the evening and I told her. I told my mother over the phone. I called my sisters. (51 year old female)

The same patient, a 51 year old female, explained why it was easier to disclose over the phone:

Just, just, yeah, but it is different when you are actually looking at the person, you know, and you just kind of see them just, you know, look all blank trying to absorb the information, so I guess in some ways it probably was a little easier to do it over the phone, because then you, there is that little bit of a, that distance of while they are absorbing it mostly, in fact I think, yeah, probably it's a little easier. I told my dad over the phone.

Many patients explained that they told family members face-to-face. However, some patients told family members individually while other patients told their family members in groups. Those who told their family members in groups explained the experience this way:

We was at my brother's funeral home. I mean, you know, and so I told them while we was at that meeting. That's all. We have, we be together all the time. Like I said, my family be together all the time. (66 year old male)

When the doctor told me, the day he told me. They just came over and I just told them all. (75 year old female)

Those who told family members individually explained how they told.

I told my husband when I came home. Did I go, I went to see my daughter, and then I told our son and daughter-in-law, I told them in person. (51 year old female)

No, it's maybe one by one because that's the way they did; they didn't come all at one time. Like I tell this one when they come over and the next one I tell her like that. That's what I did. (76 year old male)

Similar to the section on disclosure experience, late diagnosis of colorectal cancer appeared to impact the communication context causing patients to explain their diagnosis to their family members after they started treatment or while in the hospital.

I told them right after the surgery. I didn't know I had cancer. (54 year old female)

When I came out of recovery ... I told them because they told me what they took out, so they was all there. I told them. (60 year old female)

And so, they came to the hospital. We had our own private time to talk about it. Nobody imposed upon that time. (48 year old female)

Expectations and Reality of Disclosure. This portion of the interview focused on how the patients felt after revealing their diagnosis and what they expected from telling their family members about their diagnosis. Most of the patients said that they felt relief. Responses to the question about how they felt after revealing their diagnosis included:

I guess relief would be a good word. (51 year old female)

I felt relief in telling her, yes, because I figure, I figure she's going to be here anyway, you know. ((laughs)) And she's going to talk to the doctors, and you know, and she did, yeah. (89 year old female)

I felt relieved. I felt a burden was off my shoulders, you know what I mean? (76 year old male)

One patient expressed that she felt uninformed:

I just wanted to know more information, where it's going to be because they was acting like it wasn't real serious and then when it's like your mom had it (also) so it IS serious. So, it was like I stayed in that stage for a while. (27 year old female)

A couple of patients felt the need to pray after disclosing their diagnosis:

So I learned to pray, to read my Bible, and my pastor came for three days in a row and prayed, read the Bible, had prayer meetings, until I got to be all right. (54 year old female)

Well, you know what, I was just peaceful when I told them because when I told them I had cancer, he told me I had cancer, I was like well, you know, and I prayed about it, so I was peaceful with what I had to do. Either way, I was at peace. (59 year old male)

When you're facing a crisis, sometimes it's not about this or the world is saying, or who knows what, but sometimes we just have to get in touch with the Lord. (65 year old female)

Patients were also asked how they expected their family members to respond to the news of a colorectal cancer diagnosis. Though patients said they prayed after disclosing their diagnosis, only one patient said that he expected prayer.

Like I told somebody, it's like when you get sick, all prayers help, as far as I am concerned. I want people to pray for me, you know, because I just don't want to have to go through that by myself. (59 year old male)

Most patients expected other forms of emotional support, the expectation that their loved ones would provide empathy, love, trust, and show concern.

I didn't expect anything else, except to be here and be with me at least a week or two, you know, after. Of course, if she hadn't been here, my granddaughter would have been here. (89 year old female)

I expected they was going to come visiting, you know, see about me, which they did. (70 year old male)

I expect them to take it and, take it and be strong with it, you know what I mean? And be strong with me. Because I needed their strength as much as they needed my strength. So I told them, you know. (76 year old male)

Patients were asked to describe what FDRs actually did for the patient after learning that the patient needed treatment for colorectal cancer. Patients expressed a range of types of support including appraisal, emotional, informational and instrumental support. Reports of appraisal support or receiving information for self evaluation, constructive feedback, affirmation (a positive statement or judgment), and social comparison support are below:

They was just saying it's something that God planned. You know, it's something like it's out of your control, you know? (54 year old female)

Well, daddy-they just called me and said Daddy, we're going to beat it because you caught it in time. You didn't wait until it spread. So, my wife and my children, they just went on to war with it, you know. (76 year old male)

Patients also reported that they received emotional support including love, trust, and care:

I think for them-for all of us it was just a sense that, you know, we could kind of be here and go through it together, because I would have been probably really scared up there by myself, and you know, even my husband and my daughter and her kids were there, but you know, you have your mama ((laughs)). (51 year old female)

...she was with me the whole time. Every day I was there. She worked but she just, afterwards she came there, at night she stayed there, and so I'm so grateful after that. (59 year old male)

Oh, they was there the night I went up to the surgery and up until I came home. They go home and rest, because they got kids, so they'd go home and they'd rest, and they'd come right back. (54 year old female)

Informational support in the form of providing advice and suggestions that a person can use to address problems was described by patients. One patient who was diagnosed with cancer at an unusually young age described some advice given to her by a family member:

So my Auntie, she's like you need to talk to a counselor ((laughs)). So she had me, she called the counselor for me, and she was like you need to talk to the counselor about this situation and that way you get everything out. And you know, supportive, "You should not be scared, and everything's going to be okay." (27 year old female)

Another patient also described some of the advice she received from family members:

Well, when my daughter came I had told her that I had cancer. She said mom, don't worry about it because God still is good, you know, and he's not going to take you yet. (54 year old female)

Patients said that FDRs displayed instrumental support in the form of providing tangible aid such as cooking, cleaning, and transportation more than any other type of support.

My mom helped me a lot, in the worst months. You know, she cooked for me because I couldn't really move around as much, but my mom, at the age 70 almost; she cooked for me and everything. And my daughter would come over or I would go out there and stay, but I had a lot of support actually. (63 year old female)

Take out the trash, more so than what they used to do. I didn't have to say, "Take it out." You know, clean up, pick up behind themselves. I didn't have to do any of that kind of stuff. (54 year old female)

They kept cooking the food to see, to eat for me. And they support me, and read the Bible to me. And they support me, they clean up. They support me any kind of way that I needed them there, they did. And so I'm appreciative for those two little girls for that. (48 year old female)

Patients were asked how their family had responded to them since their treatment ended. Patients explained that their FDRs continue to provide emotional support in the form of showing concern through phone calls and checking up on their health.

Well, they all keep asking me how I feel, are you feeling sick or anything. I said no, I feel normal. Every now and then I get irritated with my, you know, the feeling. (70 year old male)

Good. Yeah. They call me every morning. My daughters call, and my sons called me, you know. It's more like a closer thing. It's not like "I forgot." They call. (76 year old male)

Well, good, and they come around, they come around a lot. As always, they always come around a lot. And every time I see my sons, "Oh, mom, how are you doing, mama?" (65 year old female)

Another patient said that she continued to get instrumental support from their family members:

My daughter, my sons takes me to work and my daughters pick me up...I still work on a regular basis... (64 year old female)

Patients also reported that their family members reverted to treating them “back to normal” or as if they were never ill:

Fine. Hmm, well, they, I ((pause)) I don’t know why I guess I don’t expect you know for them to do for me, especially things that I can do for myself. (64 year old female)

Oh back, I’d say, back to the same, you know. You aren’t a boy. Well, I don’t know if you know how boys are, but oh my goodness, oh! They are back the same, back to the same. It’s like mama has never been sick before. (54 year old female)

Most of the patients in this study were positive about their decisions to share their diagnosis with their family:

I feel good about it... Because, I mean, it’s nothing really to hide, you know. There’s nothing really to hold back or hide with, you know, when you got cancer, you know, a lot of people do, but I don’t feel like that, you know, and my family don’t feel like that. They support me, you know. (63 year old female)

Yeah, I’m happy, I’m happy I told. Yes I am. I’m happy about it... I don’t know, you know, I don’t know, if it went by why should it be such, why would I want to keep it so secret? Why? (75 year old female)

Yes, I did the right thing... I did the right thing... Because if you are going to be a family, you don’t hide. You share. The good, the bad, you know. You share. (76 year old male)

Effects of disclosure. An important goal of the patient interview was to understand the effect of the patient’s diagnosis on his/her family members. Patients were asked the question, what type of effect do you think disclosing your colorectal cancer diagnosis has had on your relatives? Many patients felt that that by sharing their diagnosis, family members now have more awareness and understanding about colorectal cancer. For example, patients said:

Well, I mean, I definitely feel like they are all aware that, you know that they are aware of colon cancer. And I mean I think, you know we were pretty young when my grandfather had Colon Cancer, but you know they are all aware, they are committed to getting regular checks, you know getting their colonoscopies, and

my daughter, she is like calling me when she gets to that, when she reaches that ten year mark. (51 year old female)

I think it just kind of created awareness. And then we've been kind of making sure that we share our health information anyway because we found that we kind of got these, you know different things that us tend to start, we're seeing it, it's running through the family, you know. (65 year old female)

I really think that that hurt us. We weren't exercising like I should have been, you know and things like that. But now, you know, they are physical. They like to go out and do things, you know, because most of them they just sit around and watch a game or something like that. But they like outside stuff now. They like to go outdoors and do things. (54 year old female)

Patients also felt that going through colorectal cancer treatment made them become even closer to their family:

You know, I guess the bonding that happens when you kind of go through something like that. (51 year old female)

It's like-we are strong. (76 year old male)

I think it pulled us closer together, you know, that to think that you're too busy, where I was saying earlier, you're too busy to eat lunch together. Everybody's going to work. Everybody going to work, and everybody's too busy. So I think it had an affect on her. How important is it to have lunch with your mom? You know, my mom had already passed away at 59. Our family is not very long. So how important is it to make time for lunch, make time for Clearwater, Florida, to enjoy that beach and sunshine and to make time for the little things. And to make sure you talk about it, because if you don't talk about it, that doesn't make it go away either. I think it had a good affect, actually. (48 year old female)

Patients also were asked if their family members had been screened as a result of learning of their CRC diagnosis. Twelve (n=12) patients said that their family members were screened. Comments from those patients who said that relatives had been screened are below:

...all from my experience my sisters immediately went and had Colonoscopies. They had immediately did. (51 year old female)

And two of my brothers and two sisters went and got tested, and they came back clear... And my other brother, he had his done recently, my brother and I, he had

had his done about three months after I did. So, we all getting it, everybody's getting it done. (66 year old male)

I told all of them. My daughter takes it. My daughter just took all her tests, and had her teeth done, and the whole nine yards. She was telling me the other day, she's done it all. (65 year old female)

Other patients felt that their diagnosis had no effect on their FDR's screening behaviors and they have not been screened for colorectal cancer:

No, my oldest brother's, my second oldest brother is supposed to have one, get tested, but then I think he chickened out, his wife said ((laughs)) and he never went... So he missed the appointment, but I think was scared about it... They just can't believe it. They just, I think it affected them a little just to think about it, but they've moved on. They are like, 'Okay, nothing happened, I haven't felt no symptoms.' I still tell them that you need just to go get checked out. (27 year old female)

None. Uhn-unn. They should have, what they should have done, my two daughters, was went and be tested for colon cancer. In fact, the doctors told them to, but neither one of them have gone yet. (63 year old female)

Some patients were unsure if their CRC diagnosis disclosure had an effect on their FDRs.

They never said anything to me about it. No, I sure don't (know if they have been tested). I want to tell the truth, no. (70 year old male)

I don't know. I haven't talked to them about that. (80 year old female)

I don't know. I can't say because it don't seem like they, you know, like they are bothered, but I don't know. (75 year old female)

Four patients were hopeful and believed that their FDRs planned to get screened sometime in the future:

All of them said they was going to get tested anyway. So it's just a family thing. Everybody going to do it, but at a time, you know, one of my brothers, my brother that has a church, he had made an appointment already to get his colon cancer done. (66 year old male)

Yeah, my, both of my daughters said they are going, and I mentioned it to my sons and one of them said he is going. (75 year old female)

Yeah, my sons, you know. I have two boys, and they are really up on it now, you know... They plan to get it. (76 year old male)

Patients also took an active role and suggested that their FDRs get screened and expressed a desire for their family members to get screened.

Yeah. My children and I talked about it. I told them that they may have at what age they needed to start now with having being tested. (64 year old female)

I'm trying to encourage them to do it, you know... But I let them know that, you know, it could hit anyone, so this is, you have to take it seriously. (54 year old female)

I know my sisters, they were both like, "Oh, I'm making an appointment. I'm going there." You know, and I'd say, "Yeah, you need to go get screened." (51 year old female)

Current perceptions of colorectal cancer. Patients were asked how does sharing a diagnosis of colorectal cancer compare to sharing other secrets or private information that they had to share with family members in the past. The patients in this study had a difficult time answering this question directly. Patient answers to this question are below:

It was easy to talk about it. It wasn't nothing private about it. (66 year old male)

I guess we tend to be pretty open, so I didn't consider it something that I needed to keep secret, or be afraid to tell them, or feel embarrassed about or anything. (51 year old female)

I didn't hold it from anybody because I know some of my coworkers have gone through cancer, I didn't know what type of cancer they had, but I was glad they let me know because I could pray for them. Like I told somebody, it's like when you get sick, all prayers help, as far as I am concerned. I want people to pray for me, you know, because I just don't want to have to go through that by myself. Not just the family members. Everybody, even my aunts. They go to another church, but they put me on their prayer list. I'm sorry, I just, that's my feeling. Some people don't feel like that, but that's just how I was brought up, you know. Prayers, prayers help, and I didn't hold it back from anyone. (54 year old female)

Finally, patients were asked, “Since your diagnosis, what comes to mind when you hear about colorectal cancer?” Most patients thought about colorectal cancer education and prevention:

What comes to mind is I wish we were more educated about it-and we are just finding out about it... If we pay more attention to it, you know, it's better for us, you know. You've got a better chance. But when you are ignorant to it and you don't want to pay a, no attention to it, “well, ain't nothing wrong with me.” That's when it really hurts. (76 year old male)

That we should always, you know, take care of our bodies, you know, get tested... When I hear about it in the news and see it on television and see, it's becoming too common. It's becoming, it's something that we are eating, or something we are dealing with, that causes it. (65 year old female)

It's a successful cancer, I think. Eating habits change, changing eating habits, exercising, you know, and I think it's a cancer now that, I'm not going to say that it's licked because cancer is cancer, I don't think that anybody is safe, you know. And I just think it's one of those cancers now you can say that, like Tuberculosis is now, you can say that you are going to live. You can live with that. If you do what you are supposed to do, you can live with it. And that's what I think about it. (54 year old female)

Others discussed the lasting effects of their treatment:

I just hope they got it all when they operated. (70 year old male)

When I hear colorectal cancer, I think about, to be honest with you, the people that get it in my age group, at within that age group where the souvenirs of cancer survivors-at least the souvenirs of colorectal-colostomies. I don't think that I would give anything to change surviving cancer, but at the age that I am, in middle age, why did I think it would be more acceptable to have a colostomy souvenir for my cancer survival in my later years than in my middle years. It will lead you to not be able to figure out intimacy. And it will lead you to still have to struggle with self-esteem. Well, self-esteem struggling with is easier than life and death terminal bed. So if you get to the point between terminal and colorectal where the rectum is diseased by cancer, then you throw the rectum away ((laughs)) and you deal with the intimacy problems every step you can. There are supports out there that tell you how to do it. And, but it's hard for my age group, I think, to get the souvenirs of cancer and to try to live through, you know, a happy, joyful, intimate life. (48 year old female)

Section II: First-Degree Relatives

Age, marital status, and health insurance. The first-degree relative (FDR) sample consisted of 16 adults – 2 men and 14 women who had a first-degree relative diagnosed with colorectal cancer in the past 5 years (2004-2009). To be eligible for the study, the FDRs could not have a personal history of cancer. One FDR refused to complete the demographic section of the study. Ages of the relatives in the sample ranged from 31-72 with a mean age of 47 and a median age of 44 (see Table 5).

The majority of the total FDR sample were married (n=10), one was divorced, one was widowed, two had never been married, and one was a member of an unmarried couple. FDRs were also asked to indicate their insurance status and type of insurance. All but one FDR indicated that they had insurance. Most FDRs had private insurance (n=7), four had Medicare, one had Medicaid, and two had insurance through the U.S. Military.

Social economic status. In order to examine the SES, FDRs answered questions about education, employment status, and annual household income (see Table 6). The majority of the total FDR sample were high school graduates, with six obtaining a high school diploma, three having some college or technical school education, one completed college, and three completed graduate or professional school. Most FDRs were employed for wages (n=9), one was out of work for more than one year, one was a student, three were retired, and another was unable to work.

Four FDRs had incomes of less than \$10,000, two had incomes of \$10,000-\$25,000, one had an income of \$25,001-\$35,000, four had incomes of \$50,001-\$75,000, three had incomes of \$75,001-\$100,000, and one had an income of over \$100,000.

Table 5: Sex, Age, Relationship, Marital Status, and Health Insurance (FDR)
(N=16)

Variable	N	%
Sex		
Male	2	12.5
Female	14	87.5
Age		
30-39	4	25
40-49	7	43.7
50-59	1	6.3
60-69	2	12.5
70-79	1	6.3
Missing data	1	6.3
Relationship to Patient		
Brother	1	6.3
Son	1	6.3
Sister	6	37.5
Daughter	8	50
Marital Status		
Married	10	62.5
Divorced	1	6.3
Widowed	1	6.3
Never married	2	12.5
Member of an unmarried couple	1	6.3
Missing Data	1	6.3
Health Insurance		
Yes	14	87.5
No	1	6.3
Missing Data	1	6.3
Health Insurance Type		
Medicare	4	25
Medicaid	1	6.3
Private	7	43.8
Military	2	12.5
N/A	1	6.3
Missing Data	1	6.3

Table 6: Education, Employment Status and Annual Household Income (FDR)
(N=16)

Variable	N	%
Education Completed		
Some high school	2	12.5
High school graduate	6	37.5
Some college or tech school	3	18.8
College graduate	1	6.3
Graduate or professional school	3	18.3
Missing Data	1	6.3
Employment Status		
Employed for wages	9	56.3
Out of work for more than one year	1	6.3
Student	1	6.3
Retired	3	18.8
Unable to Work	1	6.3
Missing Data	1	6.3
Annual Household Income		
Less than \$10,000	4	25
\$10,000-\$25,000	2	12.5
\$25,001-\$35,000	1	6.3
\$50,001-\$75,000	4	25
\$75,001-\$100,000	3	18.8
\$100,001 or more	1	6.3
Missing Data	1	6.3

Telephone Interviews

Semi-structured in-depth telephone interviews were conducted with the first-degree relatives of colorectal cancer patients from May 2009-August 2009. The interviews were conducted with the use of an interview guide (Appendix E), which included a list of questions grouped by topic and domain. The approach to the interviews was the same as the patient interviews in that they were conducted with a preformulated interview guide, and answers to those questions were allowed to be fully expanded at the discretion of the interviewer and interviewee, and could be enhanced by probes.

All sixteen of the interviews were recorded. Each interview lasted approximately 15-30 minutes.

First-degree Relative Telephone Interview Findings

Disclosure experience. The first part of the interview focused on the FDR's experience with learning that his/her family member was diagnosed with colorectal cancer. This question was posed in a manner for the participant to answer freely. As expected, the majority of FDRs had a difficult time hearing the news and ultimately accepting the diagnosis. They expressed shock and concern. Some of the FDR's reactions are expressed below:

Well, I was concerned. I was, because you know it's not the first person in our family that had this problem with colon cancer. (68 year old sister)

I was actually shocked to find out because he is one of the healthiest people that I know. He is the only person in the world who eats cottage cheese... So I was really shocked when I found out that he had cancer. Not that your diet has anything to do with it, but just because he's so health conscious. (38 year old daughter)

It was devastating, traumatic. I wasn't expecting that. (44 year old daughter)

FDRs were then asked about the first three things that came to mind when they learned about their relative's colorectal cancer diagnosis. This question was asked to gain an understanding of the FDR's thoughts about CRC prior to their relative's colorectal cancer treatment. Similar to the patient group, the majority of FDRs were concerned with death and were unsure if the patient would be able to survive the disease. A few of the FDRs' comments about death include:

Of course, you know, death crosses your mind, and you know... (42 year old daughter)

I guess the first thing was I was going to lose my dad. (45 year old son)

Was my dad going to make it, you know, what's going to happen? (32 year old daughter)

FDRs were also concerned about the treatment for the disease and the effects of treatment on the patient:

How long is he going to have to do medication? And things like that. (45 year old son)

What were her care options, and that was probably the biggest thing. (42 year old sister)

Is she going to have to go through, you know, all the usual things, like losing her hair, chemo, and all of that? (31 year old daughter)

One FDR expressed concerns about her own health given the frequency of colorectal cancer in her immediate family:

When I first learned it brought concerns to me because my mom, she also had colon cancer, and one of my aunts. That brought a concern to me because I know that I'd probably be a higher risk. (32 year old daughter)

Two other FDRs were less concerned with death, and expressed more hopeful thoughts when they learned of the colorectal cancer diagnosis:

And I just said like she was going to be alright. I felt it was going to be alright. So I just thought on the positive side that, you know they were alright. I know a lot of people, you know, that had it and they came through it, you know. (71 year old sister)

The doctor would just treat him, you know, so it didn't bother me too much. (sister of unknown age)

FDRs were asked who told them about their family member's diagnosis. This question was important to learn if patients disclosed information about their diagnosis on their own or if FDRs were told by a third party. A side-by-side comparison of patient and FDR responses is provided in Section III. It was found that the majority of FDRs (n=8) in this sample were told about their family member's colorectal cancer diagnosis directly by the patient.

Four FDRs reported that they were told by other family members and four FDRs reported that they were told by the patient's physician. Examples of answers from those who were told by other family members included:

I think his wife told me. He had gone to the doctor, I think, and came home and she called me. And I remember because I was actually at a workshop. (38 year old daughter)

When she first came down with it, they (family members) really didn't tell me really what it was. They just told me she had to have surgery. And after she had surgery and I, you know, I found out what it was. (71 year old sister)

Those FDRs who were told by the patient's physician explained how they were told:

The doctor told my sister and me that he had the cancer, and that he took pictures and he showed the pictures to us. (53 year old sister)

The doctor just examined him and then he called us all in and we all sat around a table, so he explained, you know, what was happening, and he said what he would have to do and things like that. (68 year old sister)

I couldn't remember the doctor's name, but the first time she had it, he was very abrupt, and he explained to me very briefly, and I just felt like a long walk, a long,

long way back to my car. I just couldn't believe what he was telling me. (43 year old daughter)

It was also important to find out the FDRs' perception of why the patient wanted them to know that they were diagnosed with colorectal cancer. In the cases where FDRs were told directly by the patient, most FDRs believed the patient wanted them to know because of his/her existing close relationship. Examples of this belief included:

Well, because, we was always, we was close. My whole family. We was very close, and we can't let cancer and stuff like that keep us from each other. (68 year old sister)

Just because I'm his sister and kind of let each other know what's happening with us. (68 year old sister)

We always talk about, you know, nearly everything, so you know. (71 year old sister)

The next most common belief held by FDRs of why the patient told family members about his or her diagnosis related to the patient's concern about the severity of the disease and uncertainty about surviving colorectal cancer.

I think when he, when he got like bad on, when it came surgery time, you know he did, it was just like the point where you know he had to let someone know what was going on. (42 year old daughter)

I think at one time she was... She thought for sure she had it bad. (68 year old sister)

Because she was concerned. She didn't know how bad it was going to be, you know what they was going to find in her. Polyps or, you know, things they were going to have to take out her Colon or not. (53 year old sister)

Communication context. FDRs were asked to describe the environment including the time and place where they were told about their relative's colorectal cancer diagnosis. FDRs expressed both positive and negative experiences with being told. A few relatives found out face-to-face while others were told over the telephone. Three FDRs

found out while at the hospital or doctor's office at the same time as the patient. In two of the cases, the reason was due to late diagnosis. One FDR described the status of the patient when he/she was told in the hospital.

... she was out of it. She was, she had had the, by the time I had got there, they had just pushed her into surgery, and she really was out of it. The only thing she could do was like nod her head. (45 year old daughter)

This same FDR felt guilty because she was not at the appointment when the doctor suggested that her mother should have a colonoscopy.

Then the doctor said that on one of the visits that I didn't go with her that he had actually said that he wanted to set her up, to schedule her for a colorectal screening...she had never been screened for it. (46 year old daughter)

The majority of FDRs (n=9) were told about their family member's diagnosis over the telephone compared to those who were told in the hospital (n=3) or face-to-face (n=4). FDR's explained:

Well, that was the most convenient way to tell me at the time, because I wasn't there. Now, they could have called all of us over and sat down and told us about it, but it was just easier over the phone. (38 year old daughter)

Well, it was done over the phone; he called me on the phone and talked to me. (45 year old son)

She told me over the phone, so I was in the house on the phone and she was at home, and she was just sharing. (42 year old sister)

FDRs also expressed what they thought were the positive consequences of being told over the phone. Being told over the phone allowed FDRs to hide their initial reaction from the patient and not observe how the patient reacted to the news of the diagnosis.

The only good thing that I could say about that is that-sometimes you are not able to see how the other person's emotions are, so it's not as hard, you know. (32 year old daughter)

Well, the good thing is I guess that she couldn't see my kind of shock. (42 year old sister)

It made me feel good because she was, you know, she wasn't depressed about it or nothing... I know she was strong, so I just, you know acted strong with her. (71 year old sister)

Reaction to disclosure. Also important for this study was to understand how FDRs reacted to the news of their relative's diagnosis. FDRs were asked, "How did you react when you first learned about the colorectal cancer diagnosis?" As expressed in the section on the disclosure experience, most FDRs were in shock:

We were just shocked, you know. There was really nothing you could do. You know, you just, you're like shocked to hear the news. (42 year old sister)

I just said, "Really?" and kind of stood there with my mouth open for a minute. (44 year old daughter)

Again, it was devastating, you know, and I'm saying I was in shock for a minute. (42 year old daughter)

FDRs were also probed to find out if they were empathetic or if they offered to do or say anything to help after the disclosure. They expressed gestures of various types of support. Some participants expressed informational support through the provision of advice, suggestions, and information:

The only thing I told my dad was to be strong, and I told him, you know, I had confidence that he would beat it because like I said my dad is a very confident person, so very strong-willed, so I told him, you know, do what the doctors tell you to do. Make sure you are following their advice, and you will be okay. (45 year old son)

Well, later on that night I came home and I went on my, looking it up to find out, because I think it was like stage 3 or 4, so I started doing my own research to find out. What is Colon Cancer? What is Stage 3? Where do we go from here? What is the treatment? What are some of his options? So I did my own research, and my sister was doing her research, and we kind of compared notes. Okay, well this is what I found, and what did you find, and there were some similarities about what needed to be done. (38 year old daughter)

Instrumental support in the form of tangible aid was also expressed.

We offered you know to help and you know to help with his drugstore, you know work around the house. But you know, it's been like that with some older people, when they are used to being, you know, independent, they really don't want too much help. (42 year old daughter)

Anything she needed doing, we was there. Whatever she asked me. Bring her food, take her somewhere, run errands. We did anything for her. (68 year old sister)

...when she was in the hospital I'd go out there, and you know, and stay be talking and she'd be wanted me to start giving her stuff and start taking it to her. (31 year old daughter)

Emotional support or the provision of empathy, love, trust and care was widely offered among this group of FDRs:

I let him know that we are thinking about him, and you know, in touch with him and checking on how he was doing. (32 year old daughter)

I went over there, you know would go over there and visit her young ones, and even see when she was in the hospital I'd go out there, and you know, and stay and be talking and she'd be wanting me to start giving her stuff and start taking it to her. (71 year old sister)

I just let her know I was there if she needed me. (42 year old sister)

Prayer and faith in a higher power was also expressed by FDRs in this study.

FDRs were vocal about giving support in the form of prayer to their family members diagnosed with colorectal cancer. It was mostly used as a way to cope with the news of the colorectal cancer diagnosis.

No, I just, I didn't cry, I just prayed about it, you know. (32 year old daughter)

You know, I just, well we just had to take it and put it in God's hands and that was it. (68 year old sister)

The only advice I had was she had to trust in God through it. (68 year old sister)

Impact of Disclosure. Many FDRs (n=11) reported that their family member's colorectal cancer diagnosis impacted their health positively, created an increased

awareness about the disease, and encouraged timely colorectal cancer screening behaviors. A few patients expressed how learning that colorectal cancer runs in the family had impacted their health behaviors.

Yes, I do work out, where I wasn't working out and stuff, I do work out. We did start watching our diets around the house a little bit. I'm not going to say, we're not healthy people, but you know, just things that we eat, you know, to prevent other illness... I'm working harder at it now and before I just always said, you know, I'm going to stop smoking one day. Now I said I would stop. (44 year old daughter)

To take better care of myself... try to eat right and exercise. (45 year old daughter)

Oh, I run, I play racquetball every day. I run, I watch what I eat. I try to stay away from fried foods, and I try to, I try to get on the deal with my mom, like the fruits and the- it's hard. (43 year old daughter)

FDRs (n=5) said that that their family members played an active role in encouraging them to get screened and talk to their physicians about colorectal cancer.

Some suggestions that FDRs recalled included:

Well, she said that I needed to talk to my doctor to have myself checked out. (46 year old daughter)

One of the things that my dad started letting us know, the males in our family, that we needed to go get this checked out. (45 year old son)

Probably it's the only reason why I was even thinking about it, because I mean she says that the doctors encouraged her immediate family members to get screened ten years earlier than when she was diagnosed... (31 year old daughter)

As a result of encouragement from patients and learning that colorectal cancer impacted their families; FDRs expressed an interest in getting themselves screened for colorectal cancer. Several FDRs (n=9) reported that they consulted with their physicians and informed other family members about their possible risk for colorectal cancer:

So I think the only thing I was worried about then was, you know, maybe I need to get myself checked out. (45 year old son)

Well, I scheduled myself for my first Colonoscopy. (42 year old sister)

I informed my doctor. I let my sons know that it's a possibility that they may need to be (checked out), that they become older... (44 year old daughter)

Three other FDRs said that although they were aware of the disease they did not have all the information they needed in order to effectively prevent colorectal cancer:

Well, I try not to, well I do exercise, but I am still concerned about, you know, both my parents being diagnosed, and having colon cancer. I really don't know what, you know, what steps you are supposed to take. (32 year old daughter)

So it made me, you know, take more heed, but I still didn't do as much research as I probably should have or could have. (32 year old daughter)

It had a lot of impact because the first thing-well, then you start thinking, is that hereditary? Will my children have it? Will I have it? Is this a one-time deal? Is it just individual cases? Where does it go from there? (38 year old daughter)

Other FDRs (n=4) concluded that the patient's diagnosis did not have any impact on them and they would not do anything differently about their health as a result of learning about their family member's diagnosis.

I never planned on going anyway... Am I concerned about my OWN health? Not really. (32 year old brother)

No, not that I know of. Nothing that I know that I need to do differently. (71 year old sister)

No, it really didn't because, I don't know, she just said it wasn't serious. (68 year old sister)

Current Perceptions of Colorectal Cancer.

The concluding question of the FDR interview asked, "When you think of CRC now, what comes to mind?" FDRs mentioned family and the ability to survive colorectal cancer. One comment about family history was:

My family. I mean, that's about all that really comes to mind. My mom had had it and now here I think it's not just my mom that had it, my dad has had it, and that's basically, you know, some of my concerns, as far as things that come to

mind. Two of my, you know, biological, you know parents have had Colon Cancer so that's the first thing that I listen. If I hear something about it, I will listen. (32 year old daughter)

In terms of survival, FDRs had a positive outlook of CRC as a result of having a family member survive the disease with few complications:

I think it is something that you can deal with and you can get through. It's not like, "okay, this is the end of the world." (38 year old daughter)

I know it's one of the cancers that, you know, if caught soon enough, it can have a very good outcome in many cases... (42 year old sister)

To keep it going, you know, keep whatever tests for the problem. The great thing, even though they can test you for problems, you can survive it. (68 year old sister)

Section III: Family Group Comparison

Description of family groups. There were five family groups analyzed for this study. A family group consisted of a patient who had **two** or more FDRs participate in the study. There were three female and two male patient families analyzed. Each individual's responses were analyzed to compare the similarities and differences among the responses of the patients and corresponding FDRs within each family.

Family group 1. Family group 1 was comprised of a 51 year old female patient, her 31 year old daughter, and her 42 year old sister. The patient's responses were consistent with her FDR responses and it appeared that the patient had a good recollection of her diagnosis experience. The description the patient gave about when and how she told her family members corresponded with her FDRs' memories of the event. The patient remembered her family being shocked by the news of her diagnosis and the FDRs also expressed their shock and fear upon learning of the diagnosis. The patient felt well-supported by her family and the FDRs expressed that they made the patient aware that they were available to give support. The patient felt that her FDRs became more

aware of colorectal cancer because of her experience and stated that all of her sisters had colonoscopies as a result. The patient's 42 year old sister stated that she has been screened for a colorectal cancer and would not have otherwise been screened, if not for the patient's diagnosis. The 31 year old daughter said she was aware of her increased risk and planned to get a colorectal cancer screening exam ten years earlier than the age her mother was diagnosed with colorectal cancer. Details of the family group 1 analysis are visible in Table 7.

Table 7: Family Group 1

Topic area	Patient – Female 51 years old	Daughter – 31 years old	Sister- 42 years old
Major reason patient told/ Patient expectations	<p>“I mean I know I definitely needed their support; I wanted them to go and get checked because my, with my grandfather having a history of Colon Cancer, you know, that was the first thing I thought, man, ooh, you know”;</p> <p>“Well, that, I mean, I don’t even know that I thought of, I mean like I just knew that they needed to know.”</p>	<p>“To encourage other family members to get screened earlier and things like that, so it is on my mind., we’re close so she was going to just out of I’m her daughter”</p>	<p>“Oh, we talk all the time; I would say just moral support, you know someone to talk to that she could discuss it with, you know, and just to kind of share the burden of the whole thing.”</p>
Communication context/Describe how patient informed FDR	<p>“I told my husband when I came home. Did I go, I went to see my daughter, and then I told our son and daughter-in-law, I told them in person. I called my mom. I didn’t see her initially. I called her.”; “Just, just, yeah, but it is different when you are actually looking at the person, you know, and you just kind of see them just, you know, look all blank trying to absorb the information, so I guess in some ways it probably was a little easier to do it over the phone, because then you, there is that little bit of a, that distance of while they are absorbing it mostly, in fact I think, yeah, probably it’s a little easier.”</p>	<p>“She told me when I went to her house.”</p>	<p>“She told me over the phone, so I was in the house on the phone and she was at home, and she was just sharing.”</p> <p>Well, the good thing is I guess that she couldn’t see my kind of shock.”</p>
FDR initial reaction to disclosure	<p>“You know, they were obviously shocked, and ((pause)) you know that they were shocked...”</p>	<p>“I was a little bit shocked; It was hard, of course, you know, hearing that, you know, my mother was sick”</p>	<p>“I guess a little fear and anxiety”; “I just let her know I was there if she needed me.”</p>
FDR support	<p>“...for all of us it was just a sense that, you know, we could kind of be here and go through it together, because I would have been probably really scared up there by myself, and you know, even my husband and my daughter and her kids were there...”</p>	<p>“Yes, you know, I didn’t offer anything specific, but you know, I told her I was here for anything, you know, I live down the street.”</p>	<p>“I just let her know I was there if she needed me.</p>
Effects of disclosure/ FDR screening behaviors	<p>“...all from my experience my sisters immediately went and had Colonoscopies. They had immediately did.”</p>	<p>“Probably is the only reason why I was even thinking about it (future screening), because I mean she says that the doctors encouraged her immediately family members to get screened ten years earlier than when she was diagnosed.”</p>	<p>“Well, I scheduled myself for my first Colonoscopy; I wouldn’t have been screened otherwise.”</p>

Family group 2. Family group 2 included a 70 year old male patient, his sister of unknown age, and his 42 year old daughter. The patient and his daughter thought about death when they first learned of the patient's diagnosis. However, the sister was not very worried because she felt that the cancer could be treated. Within family group 2, there were differences in the description of how the patient informed his FDRs about his diagnosis. The sister and daughter both said that they did not know her brother had cancer until the doctor told her at the time of the surgery. However, the patient felt that he told his family members individually, at home before his surgery.

The major reason the patient said he told his family members about his diagnosis was because he wanted support from his family. His sister felt as if the patient wanted her to "fix him up in some way," while his daughter felt as if he told his family as a last resort after he realized the seriousness of his illness. The patient felt as if his family members would not get screened as a result of learning about his diagnosis. Neither the sister nor the daughter of the patient committed to getting screened for colorectal cancer. The sister said she would consider talking to her doctor about screening and the daughter planned to take better care of herself by going to the doctor more often. A closer look at family group 2 is available in Table 8.

Table 8: Family Group 2

Topic area First things that came to mind when learning of pt diagnosis	Patient- Male- 70 years old "I don't know how it was going to come out. ((laughs)) Whether I was going to pass or what."	Sister- unknown age "The doctor would just treat him, you know, so it didn't bother me too much", "I thought it would have been worse than what it was."	Daughter- 42 years old "...of course, you know, death crosses your mind."
Major reason patient told/ Pt expectations	"I expected they was going to come visiting, you know, see about me, which they did."	"I guess he wanted, my sister and me, maybe we try to fix him or put him back together again or something."	"I think when he, when he got like bad on, when it came surgery time, you know he did, it was just like the point where you know he had to let someone know what was going on."
Communication context/Describe how patient informed FDR	"No, it wasn't hard. I just spoke out, told them what was going on and everything", "I guess before I went in the hospital. I told them then, I let them know what was going on... it was at home, we was at home, yeah... it was different times"	"With him, we was at the hospital", "The doctor told my sister and me that he had the cancer."	"That's the thing, we didn't know how bad it was, you know, until surgery time."
FDR initial reaction to disclosure	"I really couldn't tell you because-they reacted normally, I guess. They was worried about me having this cancer. They don't know what was going to happen", "They didn't show no fear or anything."	"Very, very upset, it kind of bothered me a little bit", "And it wasn't like oh, I'm going to freak out, you know that kind of thing, because I've been kind of used to that and been around it."	"Oh, it was kind of scary when we first found out. We were just shocked, you know. There was really nothing you could do. You know, you just, you're like shocked to hear the news. I was just like scared and then shocked."
FDR Support	"Getting ready to go to the doctor (FDR assisted patient), and they visited me a bunch."	"We pampered him to death. I just tried to help a person as much as you possibly can."	"We offered you know to help and you know to help with his drugstore, you know work around the house. But you know, it's been like that with some older people, when they are used to being, you know, independent, they really don't want too much help."
Effects of disclosure/ FDR screening behaviors	"They never said anything to me about it (CRC screening)...No, I sure don't (think they will get screened). I want to tell the truth, no."	"I don't know (about CRC screening). Maybe. I never even thought about it. I try not to dwell on stuff like that", "...I'm going to the doctor today, and I think I'll talk to my doctor about it and see what he advises."	"Well, I should. Maybe I'll go the doctor more and stuff, but you know. I plan on doing that."

Family group 3. Family group 3 was comprised of a 65 year old female patient and her two daughters aged 43 and 45. The patient's main reason for disclosing to her family was because she wanted them to be prepared in case she passed away. Her two daughters both said that she told them because she wanted them to take care of her assets and responsibilities. The 45 year old daughter also agreed with the patient, and said that she wanted them to be aware of what she was going through in terms of her health. The patient admitted that she didn't tell her family about her diagnosis right away; she waited for the right time and then told her younger daughter who lives nearby. The younger daughter also said that her mother told her. The older daughter who lived out of state was told by her sister at the time of her mother's surgery.

The patient felt that she was supported very well and her daughters managed everything for her while she was ill. The patient's daughters also said that they supported their mother and described the different types of support that they provided. The patient hoped that her daughters take better care of their bodies as a result of learning about her colorectal cancer diagnosis. She also believed that both of her daughters had been screened for colorectal cancer. However, neither of the daughters was screened but both planned to get screened in the future. Additional comparisons within family group 3 are listed in Table 9.

Table 9: Family Group 3

Topic area	Patient- Female- 65 years old	Daughter-45 years old	Daughter- 43 years old
First things that came to mind when learning of pt diagnosis	<p>"The first thing I was thinking, God, now I am going to have to have surgery and all of this stuff"; "I hadn't really made any provisions, it was during the school year, and I was carrying the kids back and forth to school, and my household, I hadn't made any preparations for anything like this."</p>	<p>"Being very sick and probably leaving this world."</p>	<p>"Well, it was devastating. It was, I want to say a couple of years back, a few years back, and they, it was a procedure where they took out her colon, and I thought that it would never come back. I thought it was taken care of. And it came back, they told me that it had come back, I think it was last year. It was very devastating."</p>
Major reason patient told/ Patient expectations	<p>"I think if something would happen to me, I would want to be open. I don't want it to be a surprise... if I'm sick, that I'm really sick to the point that I could be gone, I want them to be able to accept that, b/c that could be a devastating thing."</p>	<p>"If anything happened to her she wanted us to know about her insurance and different things"; "I guess she just wanted me, wanted us to know for what she was going through, what she was up against."</p>	<p>"The reason why she told me about it was she wanted me to take care of her. She always tells me about the, a lot of things. I'm the only one that's really responsible, be able to maintain her bills and stuff, and I have younger brothers that just freeloader. And I pretty much watch over a lot of things."</p>
Communication context/Describe how patient informed FDR	<p>"I didn't tell all of them right away because it wasn't time, and I wasn't in no position... But my husband, my husband would, and I told my daughter here, she called my daughter in Georgia and she came"; "...both of my daughters are mature women, and they, when they found out what was going on, then they would tell, they was able to relate to the other ones, that I couldn't personally talk to."</p>	<p>"She was having surgery when I heard about it"; "...my sister called and was telling me that hey, mama's having surgery, and I was not in the state."</p>	<p>"I was on the phone with my mother, she said well right now they tell me my cancer came back, so the argument, I forgot what I was arguing about, and then my whole day just completely fell out. I'd just rather not hear about it and now, I was trying to avoid it, but when she told me about it, it's something you can't—you just want to put it out your mind."</p>
FDR initial reaction to disclosure	Unknown	"I cried."	<p>"I tried to spend as much time as possible with her. A lot of stuff, I had a lot of stuff I wanted to talk out with her, the past, so."</p>
FDR Support	<p>"They managed everything, with the kids, and everything that I needed to do"; "...keep the house going, or, she would cook the food, make sure everything went smoothly, the children's clothes got, make sure they bathed, and was in bed at a proper bed time."</p>	<p>"I went home and helped my step dad out with the house, the housework and the running of the house.; "With her recuperation."</p>	<p>"Sometimes I go and get the kids for her and take them to the park with me and so she can get some sleep."; "I go over there and cook sometimes even though it's very difficult, because she's diabetic also..."</p>
Effects of disclosure/ FDR screening behaviors	<p>"The only effect I hope it has on them to keep in touch with their bodies and do the corrective methods to know what's going on with yourself. Because until a couple of years ago I never had a Colonoscopy"; "My daughter just took all her tests...the whole nine yards. She was telling me the other day, she's done it all; she takes, in that military, it pays good, and she gets all of her tests (other daughter)."</p>	<p>"To take better care of myself... Try to eat right and exercise; No, I haven't (been screened). Yes, I do (plan to get screened)."; "Because it's in the family, and I know I have a good chance of getting the same thing."</p>	<p>"I run, I play racquetball every day. I run, I watch what I eat. I try to stay away from fried foods, and I try to, I try to get on the deal with my mom, like the fruits and the—it's hard. No, not yet (been screened). Yeah (plan to get screened)."</p>
Thoughts now about CRC	<p>"It's becoming too common, it's something that we are eating, or dealing with, that causes it."</p>	<p>"Katie Couric's husband was diagnosed with it, she was impressing the importance of those Colonoscopies. How it's important to go get them done every year. And then the devastating end to her husband's disease."</p>	<p>"It's very dangerous I knew it occurred... I noticed that it happens a lot and neither me, nor my mother, smoke. So a lot of times I think it is the medicines the steroids they shoot up in these cows, it could be a number of things. I have to be very cautious of what I eat."</p>

Family group 4. Family Group 4 included a 64 year old female patient and her two older sisters, one 68 years old and the other 71 years old (see Table 10). Within this family group, each FDR believed that the patient disclosed her diagnosis for a different reason. The patient said that she disclosed so that her FDRs knew what they could expect from the patient including what she was able and unable to do while ill. The 68 year old sister believed she disclosed because of their close relationship and to encourage her to get screened again. The 71 year old sister believed the patient disclosed so that she could get support and assistance when needed. The patient remembered calling her sisters on the phone to tell them about her diagnosis. One sister remembered being told over the phone. The 71 year old sister remembered being told by another sister (not the patient) and was only told that the patient had to have surgery. She only found out that the patient had colorectal cancer after the patient completed treatment, not colorectal surgery specifically. The patient remembered her sisters being calm when they found out she had to have surgery and the sisters also agreed that they reacted calmly. In terms of colorectal cancer screening, the patient believed that one of her sisters had been screened. In fact, both sisters were screened previously; however one sister was unsure when she should be screened again.

Table 10: Family Group 4

Topic area First things that came to mind when learning of pt diagnosis	Patient Female 64 years old “... whatever has to be done, just has to be done.”	Sister 68 years old “I hope she will survive it.”	Sister 71 years old “I just said like she was going to be alright. I felt it was going to be alright. Because, I mean, she was strong with it, and all the kids was, you know, so.” “So I just thought on the positive side.”
Major reason patient told/ Patient expectations	“If I didn’t, it sure was going to come out anyway.”; “...that way they know what to expect, and what I can and can’t do.”; “I don’t expect you know for them to do for me, especially things that I can do for myself.”	“Well, because, we was always, we was close. My whole family. We was very close, and we can’t let cancer and stuff like that keep us from each other; she (patient) told me it might be a good idea to go ahead and get screened again.”	“I mean, just be, come to her, you know, come to her and be there if she needed me. That way, you know, if she needed something she knew I was already there. If she really need me, you know.”
Communication Context/ describe pt informed FDR	“I told my son, he was there, and then told my daughter, and the rest of my kids and my sisters. I called them on the phone.”; “...my oldest daughter she lives with her two daughters, so you know I explained to them, and talked to them, and they talked with the doctor, too.”	“Well, she had went to take some tests, and they had found one (polyp) that they got out, but there was another one she said that was, she had to go to surgery, she kind of said she had to go to surgery because they found a polyp, and it was real bad. All we knew was that she had to have surgery.”; “...she just called over the phone at night.”	“When she first came down with it, they really didn’t tell me really what it was. They just told me she had to have surgery. And after she had surgery and I, you know, I found out what it was. I think it was, I think it was my sister who told me.”; “No, (patient) didn’t talk me about it. She just said everything’s going to be alright. You know, wasn’t even praying or nothing about it.”; “...at the time I was sick, too, you know. And so, you know, we were talking about our different sicknesses or whatever.”
FDR initial reaction to disclosure	“Everybody was pretty calm and, okay. My oldest daughter, she was kind of—Upset probably.”	“I really didn’t say too much.”; “I don’t know, we just, she just said it wasn’t serious.”	“I know she was strong, so I just, you know acted strong with her.”
FDR Support	“My daughter took over cooking and cleaning actually; Everybody said if you need me, call me.”; “My daughter, my sons takes me to work and my daughters pick me up.”	“Anything she needed doing, we was there.”; “Whatever she asked me. Bring her food, take her somewhere, run errands. We did anything for her.”	“I went over there, you know would go over there and visit her young ones, and even see when she was in the hospital I’d go out there, and you know, and stay and be talking and she’d be wanting me to start giving her stuff and start taking it to her.”
Effects of disclosure/ FDR screening behaviors	“Well, it let them know that, you know, what they need to do (In terms of taking care of themselves).”; “My children and I talked about it. I told them that they may have at what age they needed to start now with having being tested.”; “I think my sister had already been tested for it.”	“I had a Colonoscopy about seven years ago... He (Dr.) told me that was good until ten years. Yes, she (patient) talked to me about going again.”; “... in the next two years I plan to go back.”	“Nothing that I know that I need to do differently.”; “I have, one time (been screened). I had mine before (patient) had hers. I had got sick and I was in the hospital, and my doctor wanted me to have it. I’ve been thinking about it (getting screened). I don’t know whether it’s time, because—how often are you supposed to take them?”

Table 10: Family Group 4 (Continued)

<p>Thoughts now about CRC</p> <p>Patient Female 64 years old “That we should always, you know, take care of our bodies, you know, get tested.”</p>	<p>Sister 68 years old “I have a good feeling because I know so many people who have survived colon cancer.”; “The great thing, even though they can test you for problems, you can survive it.”</p>	<p>Sister 71 years old “I really don’t know.”</p>
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Family group 5. Family group 5 was the largest of all the family groups and consisted of a 76 year old male patient, a 45 year old son, a 44 year old daughter, a 38 year old daughter, and a 32 year old daughter. The first thing that came to the patient's mind when learning of the diagnosis was that he could survive the illness. The patient's son and 44 and 32 year old daughters were concerned with the possibility of death. The 38 year old daughter was concerned about what to do next.

The patient stated that he told all of his children about his diagnosis himself. The patient's son and the 44 year old daughter agreed that they were told directly by the patient. However, the 38 and 32 year old daughters said that they were told by their step mother. The patient said that he disclosed so that if he became extremely ill, his children would be aware of why he was ill. The patient also expressed that he needed his children's strength and support. All three of the patient's daughters agreed that the patient disclosed in order to get support. However, the patient's son felt as if the patient was pressured by his step mother to disclose and that the patient disclosed unwillingly.

In terms of disclosure effects, the patient said that he now has a closer relationship with his children and that they pay more attention to their health. The patient's 45 year old son and 44 year old daughter recall that the patient stressed the need for the men in the family to get tested for colorectal cancer. The 38 and 32 year old daughters were concerned with the familial risk for the disease. Additional comparisons of family group five are presented in Table 11.

Table 11: Family Group 5

Topic area First things that came to mind when learning of pt diagnosis	Patient- Male 76 years old "I took it as if it were that at this age, and this stage now, that I could beat it." "Go take it out."	Son- 45 years old "...my official thought was its something real bad." "I guess the first thing was I was going to lose my dad." "...was my dad going to make it... what's going to happen, how long is he going to have to do medication and things like that."	Daughter- 44 years old "Fear. You know, afraid. We were scared, you know, because we didn't know what stage when we found out. And just the thought of losing him."	Daughter- 38 years old "How? Why? What do we do?"	Daughter-32 years old "When I first learned it brought concerns to me because my mom, she also had colon cancer, and one of my aunts. That brought a concern to me because I know that I'd probably be a higher risk." "...how bad it was, what they found... was he going to, you know, live?"
Major reason patient told/ Pt expectations	"Because they going to find out anyway. If I don't tell them, and I go down, they still going to find out." "...if you lie, then I've got to go all back over this thing, and straighten it out and all." "I expect them to take it and, take it and be strong with it, you know what I mean? And be strong with me. Because I needed their strength as much as they needed my strength."	"Because if he didn't my step-mother would have...so my guess is that he did tell me, but it probably wasn't something, you know, that he wanted to do." "...would have called me and told me that my dad had something to tell me and would have put him on the phone, and put him on the spot, so."	"I'm assuming that he told me that just to comfort me, but you know, he had said that it was nothing serious, you know." "The same, support, the support of everybody, and he didn't want everybody to worry, but he just wanted to feel like, you know..."	"I think yes, not anything but just support, Just mentally."	"I think she (patient's wife) told us because it was a concern of hers and she probably felt like we needed to know, you know, about him going into the hospital and things like that. So we can be aware; I think he just wanted attention."
Communication Context/ describe how pt informed FDR	"It is easy to talk to them. It's very easy to talk to your kids, you see. I talked to them when they were small."	"Well, it was done over the phone, he called me on the phone and talked to me, so needless to say it was a little tough for me because, you know, he handed over the phone and I had lost my mother about what, like seven, eight years ago."	"...he told me himself. He came over to see me because, again, I was out with surgery, I had just had major surgery."	"I think is wife told me; It was over the phone; Well, that was the most convenient way to tell me at the time, because I wasn't there. Now, they could have called all of us over and sat down and told us about it, but it was just easier over the phone."	"The only thing I would say about probably being bad being told over the phone is that you are not able to show any type of affection... The only good thing that I could say about that is that-sometimes you are not able to see how the other person's emotions are, so it's not as hard, you know."

Table 11: Family Group 5 (Continued)

FDR initial reaction to disclosure	Patient- Male 76 years old "They didn't fall apart; They took it and we all came together. Which we always do come together."	Son- 45 years old "...my dad pretty much minimized the thing, so he made it seem like it wasn't that much."	Daughter- 44 years old "It was devastating, traumatic. Again, it was devastating, you know, and I'm saying I was in shock for a minute."	Daughter- 38 years old "I was actually shocked to find out because he is one of the healthiest people that I know."	Daughter-32 years old "I was hurt, I was sad, being that he had to go through this"; "I didn't cry, I just prayed about it, you know."
	"They took me to the hospital, took me to the doctors, you know. We had gone out; they just called me and said daddy, we're going to beat it because you caught it in time. You didn't wait until it spread. So, my wife and my children, they just went on to war with it, you know."	"The only thing I told my dad was to be strong, and I told him, you know, I had confidence that he would beat it because like I said my dad is a very confident person, so very strong-willed, so I told him, you know, do what the doctors tell you to do. Make sure you are following their advice, and you will be okay."	"I was seeing my dad every day throughout his chemo... it was a way all the family came together, everybody flew in, so you know, he's got support from levels from all over, you know. Between the family, the pastors, friends, you know."	"I started doing my own research to find out..."; "...while he was still in the hospital I would go out there, I took him some pajamas. You know, covered him up because it's always cold in the hospital. Just anything to make him more comfortable, Take part, being there, physical support if he needed us to take him to the doctor."; "I told him, I'm here."	"I let him know that if he needed any help to the doctors or I'd try to call him every day, you know, just to show some type of support...let him know that we are thinking about him, and you know, in touch with him and checking on how he was doing."
Effects of disclosure/ FDR screening behaviors	"They call me every morning. My daughters call, and my sons called me, you know. It's more like a closer thing. They pay more attention to their health, they have to pay more attention to my health."; "No. Nobody. I'm the only one (screened for CRC)."	"So I think the only thing I was worried about then was, you know, maybe I need to get myself checked out."; "One of the things that my dad started letting us know, the males in our family, that we needed to go get this checked out."; "But I had already had an appointment set up, so there wasn't anything for me to go out and do personally. I'm retired military so I go to VA and they set it up, and so time period is like every five years or something after you hit 40."	"Well, actually, it did open my eyes to something...it brought cancer more to life because it was closer, you know what I'm saying... Yes, I do work out, where I wasn't working out... We did start watching our diets around the house a little bit...I let my sons know that it's a possibility that they may need to be, that they become older."; "I've never gotten it...Not to say that I can't get it, and especially since daddy has it... No, but he wanted to make sure that the boys did. So he kind of stressed it with the men."	"It had a lot of impact because the first thing- well, then you start thinking, is that hereditary? Will my children have it? Will I have it? Is this a one-time deal? Is it just individual cases? What does it go from there?" "No, I have not. Yes. In the future, yes., but probably like if I get over 40, to go and get screened for it."	"What impact? Because, you know, I knew my mom had it, and then when he got it and I figured that it's a little bit more serious than, you know, of you just maybe hearing about it, or whatever. So it made me, you know, take more heed, but I still didn't do as much research as I probably should have or could have."

Table 11: Family Group 5 (Continued)

Thoughts now about CRC	<p>Patient- Male 76 years old "What comes to mind is I wish we were more educated about it-and we are just finding out about it." "If we pay more attention to it, you know, it's better for us, you know. You've got a better chance."</p>	<p>Son- 45 years old "I don't know. I mean, because I really don't, I mean the only person I heard about in the news with it was Farrah Fawcett. I really don't hear about it that much."</p>	<p>Daughter- 44 years old "... what comes to mind now is knowing that there is a cure. So that's what comes to mind, that there are people out there like you and centers, and there is more support than ever before."</p>	<p>Daughter- 38 years old "...so if there is anybody who I know who has Colon Cancer, then I'll just tell them some of the things that he did when he was so successful with the treatment."</p>	<p>Daughter-32 years old "My family. My mom had had it and now here I think it's not just my mom that had it, my dad has had it, and that's basically, you know, some of my concerns, as far as things that come to mind. Two of my biological parents have had colon cancer so, if I hear something about it, I will listen."</p>
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Summary

This study was initiated to explore a topic for which little research has been conducted. Analysis of the data was conducted with the goal of answering the research questions for the study. Semi-structured, in depth, face-to-face interviews and semi-structured in depth telephone interviews were conducted to examine perceptions and descriptions of how family support and closeness to the patient impacts disclosure to first-degree relatives and how this disclosure influences the CRC screening activities in African American families.

Section I reported on the patient study goals, the first of which was to determine which factors influence a patient's decision to reveal a CRC diagnosis to a family member. In this study, qualitative methods were employed to elicit details of patients' disclosure of a colorectal cancer diagnosis to first-degree relatives and the criteria patients use to decide whether or not to disclose their diagnosis. It was found that severity of the disease, closeness to family and FDR risk for CRC were the factors that appeared to have the most influence on disclosure. The second goal of the study was to determine the utility of the Family Secrets framework and explain what decision-making criteria patients use to help them decide to disclose a CRC diagnosis. The qualitative interviews examined each construct including whether issues such as the patient's well-being, the anticipated response from the confidant, the communication context, the patient's perceived impact of the disclosure on family members, and the reward associated with disclosure influence a patient's decision to disclose. It was found that each construct from the framework was relevant and apparent in the data. The third goal of the research study was to examine what roles the four types of social support play in a patient's decision to

disclose their diagnosis to a first degree relative. It was found that emotional support had the strongest influence on the decision to disclose. Patients said that they expected emotional support from their first-degree relatives in the form of prayer, visitation, and expressions of care and concern.

Section II reported on the FDR study goals and employed the use of semi-structured telephone interviews with the first-degree relatives of the patients. The fourth goal of the research study questions was to determine how first-degree relatives perceive the information they received about the patient's diagnosis. The FDRs in this study perceived the diagnosis as fatalistic, an expression of closeness to the family, and an opportunity to provide social support. The fifth goal was to understand how diagnosed patients influence the screening behaviors of first degree relatives through the four types of support. It was found that patients influence the health and screening behaviors of FDRs primarily through informational support. Section III was a side-by-side analysis of related questions from the patient and FDR interviews guides. This analysis compared the results of the family groups from Section I and Section II in order to determine if patient and FDR responses were congruent. It was found that: patients said they were completely open while FDRs felt patients were reluctant to disclose; patients turned to faith and prayer to help cope with the diagnosis; and FDRs offered prayer to patients. There were discrepancies between patient beliefs about FDR screening actual FDR screening behavior. Further discussion of the results will be presented in Chapter V.

Chapter V

Discussion and Conclusions

This chapter discusses the results of structured interviews conducted with cancer patients and their first-degree relatives. Contributions of this research to theory and public health will be described. The limitations of the study will be delineated, along with recommendations for future research directions.

Colorectal Cancer Disparities

Cancers of the colon and rectum have higher incidence, mortality, and later stage of detection rates for African Americans than for whites (ACS, 2008). Screening is a critical measure in the prevention of CRC due to its ability to identify and remove pre-cancerous polyps that may take years to develop into cancer. Studies have shown that in African American populations, a higher percentage of CRC occurs in patients under the age of 50 (Agrawal et al., 2005; Kanna, Schori, Azeez, Kumar, & Soni, 2007). In the current research study, a large number of patients waited for symptoms before they decided to schedule a doctor's appointment or make a trip to the emergency room and two patients were under the age of 50 when diagnosed. It was also common for them to have never had a colonoscopy before being diagnosed. Instead, patients explained that they experienced pain and bleeding before they sought treatment.

Patients also explained that they felt uninformed about colorectal cancer and their treatment options before and after treatment. During one interview, the patient asked the interviewer if he really needed to do a follow-up colonoscopy after treatment. This

provides evidence for the fact that even after treatment, patients are unsure of how to prevent reoccurrence of colorectal cancer.

People who have a first-degree relative with colorectal cancer are about twice as likely to develop the disease as those with no family history of the disease (ACS, 2008). For this reason, it is important for first-degree relatives of colorectal cancer patients to understand the screening recommendations for prevention and early detection. The FDRs in the current study reported that they realized colorectal cancer runs in their families, but FDRs were unaware of how to actively prevent colorectal cancer. This is consistent with previous literature that reported that African Americans who have first-degree relatives with CRC are less likely to participate in colonoscopy screening and less likely to have endoscopic procedures before age 50 compared to whites with affected relatives (Murff et al., 2008).

Health care providers may underestimate the impact that they have on an individual's decision to get screened. Powe and Adele-Kelly (2005) reported that patients may not be aware of the benefits of screening unless their health-care professionals discuss it with them. They also state that it is possible that healthcare providers have their own beliefs, and judgments about colorectal cancer that impacts their decision to recommend screening. A previous study by Fletcher (2002) reported that physicians who do not believe in the importance of colorectal cancer screening may communicate their lack of conviction to their patients. Colorectal cancer screening can also be viewed negatively by providers due to the cost, time constraints, and lack of reimbursement (Rex, 2002).

According to the American Cancer Society (2009), a family history of colorectal cancer increases one's chances of developing colorectal cancer. Individuals with a family history of CRC or adenomatous polyps in any first-degree relative younger than age 60, or in two or more first-degree relatives at any age are considered at increased risk for CRC (ACS, 2009). A study by Kupfer, McCaffrey, and Kim (2006) found that black patients, especially men, were significantly less knowledgeable of paternal family cancer history than maternal family history compared to whites. This is troubling because one must be aware of his/her family history in order to participate in timely screening.

Disclosure

The manner in which the patients in the current study disclosed their diagnosis to family members depended on the severity of disease. Many patients in the current study waited for symptoms before being screened, and were hospitalized and/or underwent surgery before they were faced with the decision to disclose their diagnosis to family members. In these cases, the cancer was more severe, and FDRs often learned about the diagnosis and severity of disease at the same time as the patient. In some instances, the doctor informed family members waiting at the hospital, rendering disclosure out of the patient's control. This is consistent with a study by Henderson, Davison, Pennebaker, Gatchel, and Baum (2002) that found disclosure of a breast cancer diagnosis was predicted by severity of disease, with greater severity associated with more disclosure.

In contrast, patients who first learned about their CRC as a result of a colonoscopy had time to contemplate disclosure and decide whom to tell. In a study by Hallowell et al. (2005), patients described three communication strategies for disclosure of a genetic risk to their children: 1) complete openness, 2) limited disclosure, and 3)

total secrecy. In the current study, only the first two strategies were reported. Many patients said they had been completely or partially open in revealing their diagnosis. Another strategy reported was delayed disclosure in which patients told some FDRs right away, while waiting to tell others until they had more information about their diagnosis, waiting until they felt the time was right, or telling them when they felt they needed to know. None of the participants in the study reported that they maintained total secrecy.

The extent of disclosure also varied within the study population. All participants informed at least one family member about their CRC diagnosis. Some patients said they had been completely open with family members (and even some co-workers); however, in some cases their FDRs felt this disclosure was done reluctantly. These FDRs believed that the patient told them, despite their reservations, because it would be difficult to hide the illness or because they wanted the FDR to become aware of the importance of CRC screening.

These findings reinforce those of Gray, Fitch, Phillips, Labrecque, & Fergus (2000) who reported that, the perception of the other person's right or need to know about a prostate cancer diagnosis was a major factor motivating disclosure among Canadian patients. Though some of the Canadian patients in the study said it was difficult to communicate the news to FDRs, there was a felt sense of obligation to let FDRs know about their familial risk. For example, one patient in the current study who practiced limited disclosure told most FDRs but did not tell her youngest daughter because she did not want her to know that she was dying. The patient was careful to avoid using the word "cancer" in the child's presence. Another patient in the current study who displayed limited disclosure said that she informed all of her family members. However, after an

interview with her sister, it was found that the patient only told her that she was having surgery and never mentioned that she was having surgery for cancer.

Delayed disclosure also occurred among this study's patients. Some patients waited until they were sure they were going to survive the disease or had more information on the treatment options before informing all FDRs. One patient avoided telling a sister for over one year because the patient believed that her sister was favored as a child. This case is consistent with Afifi et al. (2005), who reported that individuals may refrain from revealing a secret for fear of judgment and ridicule, or concern that the information would be used against them. Unlike Afifi et al.'s (2005) findings, the patient in this study reluctantly told her sister about her diagnosis in an effort to make amends with her sister.

CRC patients reported that they often experienced distress when they contemplated disclosure of their CRC diagnosis to FDRs. Patients wanted to protect their family members from the possible stress, worry, anxiety, and fear that they believed FDRs would experience on account of their illness. Afifi et al. (2005) asserts that people keep secrets because they are afraid the revelation will hurt the target of the secret, damage their relationship with that person, or impact other family members. Additionally Hilton et al. (2009) found that telling family and friends about a cancer diagnosis was one of the hardest aspects of having cancer.

Patients in the study also said they experienced relief after disclosing a diagnosis to FDRs. This could be due to the receipt of social support that the patients in this study received from family members. Because most FDRs in the current study reacted positively, the patients may have been more likely to have positive feelings towards

disclosure. Patients reported feeling more comfortable talking about CRC to their FDRs if their prognosis looked positive. This finding suggests that one's prognosis might affect a patients' comfort with the disclosure process.

FDR Screening

Some (n=6) of the patients in the current study said they encouraged their FDRs to participate in CRC screening and to make lifestyle changes in terms of diet and exercise. This is likely because these patients understood the importance of a healthy lifestyle and early detection in the prevention of colorectal cancer.

Most FDRs reported that learning of their relative's disease influenced their screening intentions and other health behaviors believed to prevent CRC. Nine (n=9) reported that they planned to get screened in the future because of their increased risk, and some also reported that they increased their exercise, changed their diets, and made a stronger attempt to quit smoking after learning of their familial risk for CRC.

In contrast, other FDRs reported that they did not change their future plans after the disclosure. They said that they were more aware of their CRC, but they were unsure about the protective measures to take besides screening. In two cases, FDRs were also unwilling to be screened. One man, a 32 year old brother of a female patient diagnosed in her 20's, also reported his mother was diagnosed with CRC at a young age. He explained that he was fearful of finding cancer and, uncomfortable with screening procedures that involved the rectum because he believed that procedures in that area were associated with homosexuality. Men's adherence to an idealized form of masculinity can have consequences on their health when they reject behaviors that they associate with femininity or homosexuality (Courtenay, 2000). Another FDR in her seventies said that

she didn't plan on getting screened because her physician never told her it was necessary, but she did plan to discuss it during her next doctor's appointment. This case points to the importance of a physician's recommendation for screening. In a study by Madlensky, Esplen, Gallinger, McLaughlin, & Goel (2003), it was found that the strongest predictor of CRC screening was physician encouragement.

Spirituality

Prayer and faith played an important role in how patients and their FDRs coped with their diagnosis and treatment. Many patients turned to their faith in a higher power and prayer to help them cope with CRC and to improve their chances of surviving the disease. FDRs also offered prayers as a type of social support they provided to their relatives after the diagnosis.

These findings are consistent with Bowie, et al. (2004) who found religion and spirituality to be significant personal and cultural resources within many racial and ethnic traditions and offer a context for promoting health and individual well-being. For African Americans, the church plays a critical role in the lives of most African-American adults in the southern United States; it has the unique ability to meet various spiritual, economic, social and cultural needs of the black community (Blocker et al., 2006).

Contributions to Theory

This research study's contribution to theory includes the exploration of a new way to understand the disclosure process in an African American population. The Family Secrets and the Social Support Frameworks were the basis for this study, and it was interesting to find that both were relevant to the population of interest. The use of the

Family Secrets Framework is a new contribution to public health theory because it has not been used specifically to help explain disclosure of a chronic disease such as cancer.

A family secret is any information that directly affects or concerns a person but is either withheld or differentially shared between or among family members (Brown-Smith, 1998). According to Brown-Smith (1998), the family is of specific interest in the study of secrets because it is considered to be the most important social organization and emotional environment that individuals encounter. Given this assertion, it is important to understand what people consider when they reveal secrets because disclosing family secrets can have substantial influences on individuals and their interpersonal relationships (Vangelisti et al., 2001). The current study adds to the existing family secrets literature because it uses the criteria for revealing family secrets to study the disclosure of a disease diagnosis to family members. To the researcher's knowledge, there are no existing studies that have used the Family Secrets Framework in this manner. In the past, the study of family secrets typically focused on issues thought to be taboo such as child abuse or drug use. Therefore, the current study has established that this framework is useful for understanding disease disclosure. Tables 12 and 13 provide a visual representation of how the Social Support and Family Secrets Frameworks are evident in the results of the patient and FDR interviews.

Table 12: Evidence of Theory in Patient Responses

Theory Construct	Interview Question	Example of patient response
<i>Family Secrets Framework</i>		
The secret threatens one's own well-being both physically & psychologically	What was the major reason you decided to tell?	"I don't know how it was going to come out. ((laughs)) Whether I was going to pass or what."
The anticipated response from a confidant is positive	What was the major reason you decided to tell?	"I expected they was going to come visiting, you know, see about me, which they did."
The communication context creates an opening for disclosure	When did you feel it was an appropriate time to reveal your diagnosis?	"...so I guess in some ways it probably was a little easier to do it over the phone, because then you, there is that little bit of a, that distance of while they are absorbing it mostly, in fact I think, yeah, probably it's a little easier."
The impact of the disclosure on family members is positive such as receiving social support	What was the major reason you decided to tell?	"I didn't expect anything else, except to be here and be with me at least a week or two, you know, after. Of course, if she hadn't been here, my granddaughter would have been here."
When the disclosure itself brings some reward	What was the major reason you decided to tell?	"...all from my experience my sisters immediately went and had Colonoscopies. They had immediately did. "

Table 12: Evidence of Theory in Patient Responses (Continued)

Theory Construct	Interview Question	Example of patient response
Social Support Framework		
Emotional Support- provision of empathy, love, trust, & caring	How did they actually respond or react to the news?	“Oh, they was there the night I went up to the surgery and up until I came home. They go home and rest, because they got kids, so they’d go home and they’d rest, and they’d come right back.”
Instrumental Support- provision of tangible aid and services that directly assist a person in need	How did they actually respond or react to the news?	“My daughter took over cooking and cleaning actually; Everybody said if you need me, call me; My daughter, my sons takes me to work and my daughters pick me up.”
Informational Support- provision of advice, suggestions,& info that one can use to address problems	How did they actually respond or react to the news?	“My children and I talked about it. I told them that they may have at what age they needed to start now with having being tested.”
Appraisal Support- provision of info that is useful for self-evaluation (constructive feedback, affirmation, & social comparison)	How did they actually respond or react to the news?	“They was just saying it’s something that God planned. You know, it’s something like it’s out of your control, you know?”

The face-to-face interviews were used to determine whether constructs, such as the patient's well-being, the anticipated response from the confidant, the communication context, the patient's perceived impact of the disclosure on family members, and the reward associated with disclosure, influence a patient's decision to disclose. It was found that the constructs were relevant to the current study: **1) the secret threatens one's well being:** In the current study it was apparent that some patients experienced a psychological burden of carrying the news of a diagnosis before disclosure occurred; **2) the anticipated response from a confidant is positive:** Patients expected their FDRs to be nonjudgmental and were hoping for a new perspective on the challenges associated with being diagnosed with colorectal cancer; **3) communication context creates an opening:** Patients told their FDRs about the CRC diagnosis individually, in person and in groups. They also told FDRs over the telephone. Finding the right time to disclose appeared to be influenced by the family structure, e.g. whether the FDR lived nearby, the age of the FDRs, or if the FDR would be able to assist in some way. The variability of when and how a patient decided to tell family members was a personal decision which supports the notion that people are more likely to discuss personal or intimate issues in some social contexts more than others; **4) the impact of disclosure on family members is positive:** In the current study, patients wanted to inform family members that colorectal cancer runs in the family. In this context, revealing a diagnosis has the potential to save a family member's life if an FDR takes appropriate prevention measures; **5) the disclosure itself brings some reward:** In addition to prayer, patients expected some form of social support from their family members after disclosure.

Another goal of the research study was to examine the role support plays in a patient's decision to disclose their diagnosis to a first degree relative. Most patients stated that they did not expect social support from their family members to result from telling them about their colorectal cancer diagnosis. However, when further probed, those who stated that they did not expect social support admitted that the support they received was welcomed and expected. Patient descriptions of the different types of support received are also included in Table 12.

Support for the Family Secrets Framework was also found in the FDR responses (see Table 13). FDRs described several reasons for patient disclosure. It was interesting to discover that their explanations were consistent with the constructs from the Family secrets Framework. For example, FDRs believed that patients revealed their diagnosis because the secret threatened the patient's well-being, because the patient thought the FDR would have a positive response, because they had a convenient time and location to reveal, because the FDR would provide social support, and because they wanted the FDR to take preventive measures against CRC.

Table 13: Evidence of Theory in FDR Responses

Theoretical Construct	Interview Question	Example of patient response
<i>Family Secrets Framework</i>		
The secret threatens one's own well-being both physically & psychologically	Why do you think s/he told you?	"Because she was concerned. She didn't know how bad it was going to be, you know what they was going to find in her..."
The anticipated response from a confidant is positive	Why do you think s/he told you?	"Anything she needed doing, we was there. Whatever she asked me. Bring her food, take her somewhere, run errands. We did anything for her."
The communication context creates an opening for disclosure	Was the environment good for that type of conversation	"Well, that was the most convenient way to tell me at the time, because I wasn't there. Now, they could have called all of us over and sat down and told us about it, but it was just easier over the phone."
The impact of the disclosure on family members is positive such as receiving social support	What do you think your family member expected from you by telling you about their diagnosis?	"The reason why she told me about it was she wanted me to take care of her."
When the disclosure itself brings some reward	What do you think your family member expected from you by telling you about their diagnosis?	"To encourage other family members to get screened earlier and things like that..."
<i>Social Support Framework</i>		
Emotional Support- provision of empathy, love, trust, & caring	How did you react when you first learned about the CRC dx?	"I mean, just be, come to her, you know, come to her and be there if she needed me."
Instrumental Support- provision of tangible aid and services that directly assist a person in need	How did you react when you first learned about the CRC dx?	"I went home and helped my step dad out with the house, the housework and the running of the house, with her recuperation."
Informational Support- provision of advice, suggestions, & info that one can use to address problems	How did you react when you first learned about the CRC dx?	"...so I started doing my own research to find out. What is Colon Cancer? What is Stage 3? Where do we go from here? What is the treatment? What are some of his options?"
Appraisal Support- provision of info that is useful for self-evaluation (constructive feedback, affirmation, & social comparison	How did you react when you first learned about the CRC dx?	"The only thing I told my dad was to be strong, and I told him, you know, I had confidence that he would beat it because like I said my dad is a very confident person, so very strong-willed, so I told him..."

An important goal of the study was to understand how diagnosed patients influence the screening behaviors of first degree relatives through the four types of support. It was found that informational support from patients had the strongest influence on FDR screening behaviors. FDRs reported that patients advised them to get screened for colorectal cancer and to talk to their physicians about the importance of screening. FDRs also expressed that learning about a colorectal cancer diagnosis within the family increased awareness about the disease including the importance of timely colorectal cancer screening behaviors. Although the other types of support were not reported by FDRs as having a strong influence on their screening behaviors, the framework proved valuable as FDRs expressed how they reacted to the news of their family members' diagnosis. It was found that FDRs offered all four types of support to their loved ones; however instrumental and emotional support were provided most frequently.

Contributions to Public Health Practice

The current study investigated the perceived barriers, facilitators and criteria to disclosing a colorectal cancer diagnosis to first-degree relatives of colorectal cancer patients. This research is important because there has been little empirical research exploring the criteria people employ in deciding whether to reveal a family secret (Vangelisti et al., 2001). Results are especially important for the African American population given the high incidence and mortality of CRC among this group.

Though the patients in this study were willing to share their diagnosis with certain family members, the FDRs in the study described some of the challenges that the patients had with disclosure. Disclosure of the diagnosis was stressful for patients and FDRs.

Understanding the experience of the diagnosed patient is important for the design of interventions that assist patients with the disclosure process. It also highlights the patient's need for assistance coping with the impact of diagnosis. Many people go through a time of grief and sadness when they first learn that they have cancer. They grieve the loss of health and the loss of certainty in their lives (ACS, 2009). Although this coping response is normal, it is difficult for most clinicians to fully understand the experience of the patient (Jacobsen & Jackson, 2009).

In order for oncologists to communicate effectively in these difficult situations, it is helpful to assess what the patient knows and wants to know about his/her disease in general and, specifically, his/her prognosis (Jacobsen & Jackson, 2009). This is consistent with the current study in which patient barriers included fear and concern about how their family members would respond to the news of their diagnosis. These results suggest that patients should be given a firm understanding of CRC and their prognosis. Once patients have a better understanding of what to expect in terms of their treatment, prognosis, and preventing a reoccurrence, they are more confident in their ability to talk about it with their family members.

This study underscores the importance of effective communication between physicians and their patients in terms of CRC treatment and prevention measures. Some patients and FDRs reported that they relied on their physician's advice to determine whether or not they needed to be screened. Unfortunately, some patients in the current study were unclear about their treatment options and how they could effectively prevent CRC in the future. The need to develop communication strategies and tools to encourage physicians to assess the need for screening and promote it when appropriate is clear. A

study by Madelensky et al. (2003), found that the strongest predictor of CRC screening was physician encouragement. They additionally found that physician recommendation is a strong and consistent correlate of screening behavior. Patients in the current study said that their physicians never recommended screening for CRC before they had symptoms. Given this information from the current study and the important impact of physician recommendation on patient screening noted in the literature, it may be feasible to develop guidelines for physicians to promote CRC screening to patients and to incorporate screening into routine physical exams. Additionally, physicians should inform CRC patients about the possible familial risk for CRC and direct them to resources that deal with the psychosocial affects of diagnosis and disclosure.

This study also suggests that CRC patients can play an important role in communicating familial risk to FDRs. Upon learning that they had a family member with CRC, most FDRs became interested in how they could prevent it. Many FDRs requested additional educational materials from the interviewer in order to get more information about CRC. Many were screened and some reported making lifestyle changes after learning of their familial risk.

Finally, the African Americans in the study mentioned faith and spirituality as an important contribution to coping with CRC. This information is important for the incorporation of sociocultural beliefs including the role of spirituality in interventions that assist CRC patients with the coping and disclosure of a diagnosis. According to Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson (2003), a sociocultural approach to health information and messages is one in which a group's cultural values,

beliefs, and behaviors are recognized, reinforced, and built on to provide a context and meaning to health information and messages.

It is important to understand that incorporating cultural values and beliefs alone may not be enough to impact behavior change (Kreuter & Haughton, 2006). A study on tailoring cancer prevention and screening information for African American women found that only when cultural tailoring was combined with behavioral tailoring did it emerge effective in promoting mammography or increased consumption of fruits and vegetables (Kreuter & Haughton, 2006). It also suggests that health communication based on constructs from health behavior change theories may be more effective in some population subgroups when presented in a meaningful context such as culture. The current study provides evidence for the importance of spirituality in the lives of African American CRC survivors and their families. Additionally, the use of the family secrets framework in this study lays the groundwork for the future development of cultural and behavioral interventions for this population.

Overall, it is important to build commitment from communities, through community-based participatory research (CBPR) methods and to include community- and church-based interventions that are aligned with cultural norms and include community (Robillard & Larkey, 2009). Based on the results of this study, possible interventions include the development of culturally tailored navigator program for recently diagnosed CRC patients and other patients at risk for CRC including FDRs. Patient navigation is a process by which an individual (patient navigator) guides patients with a diagnosis or possible diagnosis of cancer through the complex cancer health care system to help ensure timely diagnosis and treatment (Oluwole et al., 2003). This patient

navigator program may prove effective in assisting patients who are unsure about how to prevent a future reoccurrence of CRC and for FDRs who have an interest in taking appropriate preventive screening measures.

Since the importance of spirituality was mentioned frequently in the current study, community and church-based interventions using lay health advisors may have a positive influence on CRC prevention in the African American community. The Witness Project, a program in which female African American breast cancer survivors teach their peers about breast cancer and early detection through telling their stories has shown promise for promoting the health of African Americans (Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996). It would be worthwhile to develop a similar program for colorectal cancer in which CRC survivors share their stories with newly diagnosed patients and those at high risk for the disease. Survivors could also discuss the challenges associated with disease disclosure and the potential pros and cons of disclosure.

Strengths and Limitations

The primary strength of the present study was the engagement of African American colorectal cancer survivors and their FDRs in a discussion about their internal disclosure decision-making process. Relatively little research has been conducted with African American CRC patients. Additionally, this study used a two-phase research design to study the disclosure process from both the patient and their FDR perspectives, and allowed for comparison of the results through the analysis of family units comprised of the patient results and the results of two or more FDRs. This unique contribution delves further into the disclosure process among family units. Neuman (2003) suggests that this process of observing the same phenomena from different angles or viewpoints to

get a fix on its true meaning is called triangulation (Neuman, 2003). He also asserts that it is better to look at something from several angles than to look at it in only one way.

Triangulation of the theoretical frameworks was also used in the planning of the research and in the interpretation of the data.

Given the emotionally laden nature of colorectal cancer, individual interviews were conducted to obtain an emic view of the disclosure process. Patients and FDRs were able to describe their experiences in their own words, providing insights difficult to obtain from a survey. In terms of data analysis, the researcher employed a double-coding technique which allowed for verification of codes and themes among more than one person. According to Barbour (2003), this exercise's value rests on content and nature of any disagreements rather than the extent of agreement. Barbour (2003) also states that the dialogue between team members feeds back into and informs the development of a coding frame. Such a session reproduces in microcosm the process of qualitative research itself and maximizes the analytic potential of exceptions or potential alternative explanations.

The use of the constant comparative method allowed for the development of themes which focused on how individuals interact in relationship to the phenomenon under study, in this case the disclosure of a CRC diagnosis (Dey, 1999). A benefit of this method is that the results are traceable to the data so that review of the data at a later time would produce the same results (Strauss & Corbin, 1994).

Finally the use of Atlas.ti, a qualitative data analysis software, created a greater potential for the study methodology and analysis to be replicated in future studies because it functions as a documentation center, recording all the category definitions,

coding rules, and the steps of analysis of all interpreters. The program also facilitates the recording of source detail, the time and date of the data collection, storage, and search capabilities (Baxter & Jack, 2008).

This study is not without limitations. As with many studies of African American patients, this study included relatively few men (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Hatchett, Holmes, Duran, & Davis, 2000; Thomas, Simpson, Tarver, & Gwede, 2010). Future research is needed to obtain a more in-depth look at men's experience as both CRC patients and FDRs.

The study sample was also limited by its size. The original goal for this study was to recruit thirty patients and thirty FDRs. However, the low numbers of potential participants in the sample frames made this goal difficult to reach. Reasons for patient non-participation in this study included: 1) patient was too ill to participate, 2) patient did not have time, 3) patient was not comfortable talking about his/her diagnosis, 4) patient was deceased, 5) patient moved out of state, 6) patient was not interested in participating, 7) family member interception: family member did not approve of patient's participation, and 8) patient could not be contacted by telephone. Reasons for FDR non-participation included: 1) FDR could not be contacted by telephone, 2) FDR did not have time, 3) FDR did not know patient had cancer, and 4) FDR was not interested in participating. Though there many reasons for non-participation, questionnaire saturation was reached in both phases of the study. However, theoretical saturation was not reached due to the inability to reach those patients who practiced total non disclosure. Therefore, the limited sample and lack of random selection greatly limit the ability to generalize the findings to all African Americans or to African Americans in the southern United States.

Response bias is another potential problem limiting the ability to generalize findings. The response rate for the patient sample was 39% and the response rate for the FDR sample was 80%. Everyone who participated in the study had strong family ties and disclosed to at least one family member. It is possible that patients who refused to participate were less likely to disclose their diagnosis to family members. Future research is needed to assess the proportion of African American CRC patients who fall into each category of disclosure and the reasons for maintaining secrecy.

Social desirability bias is another possible limitation. Participants may have adjusted their true feelings and experiences to reflect what they thought was a more socially desirable response given the sensitive subject matter.

Finally, the data collected in this study was self-reported and may be prone to some inaccuracy. Though the researcher attempted to reduce recall bias by including those patients who were diagnosed within the last five years, recall bias is still possible due to memory lapse or discomfort disclosing personal information. However, triangulation of FDRs and patient data helps improve the validity of the patient results.

Recommendations for Further Research

Further study in this area of disclosure is clearly warranted. Next steps could include the development of a quantitative instrument that would further capture and address the themes noted from the individual interviews. Research that captures the similarities and differences in disclosure among other ethnic groups and that examines gender differences is also needed. Exploring disclosure for other types of cancers and diseases with familial risk might also prove valuable. Preliminary findings also suggest that additional studies on disease disclosure may make an important contribution to the

literature. For example, would patients be willing to disclose their diagnosis to family members if their treatment was not as successful? Future research should also attempt to reach those patients who practice total secrecy and find out their reasons for non disclosure. This can be explored by attempting to reach patients in a clinic setting. Patients may be more likely to discuss non disclosure in a patient setting while undergoing treatment than at a later date. Further, it is important to focus on the development of culturally-specific educational materials that move beyond the visual image of racial/ethnic minority groups on the cover, address some of the attitudes, beliefs, and myths about CRC, and replace the lack of knowledge about CRC with factual information (Powe & Adderley-Kelly, 2005).

Conclusions

Using a qualitative research methodology, this study explored the disclosure process among African American colorectal cancer survivors and the FDRs with whom they shared their diagnosis. In particular the study examined the criteria people use to decide when it is appropriate to reveal a CRC diagnosis to family members, how social support impacts disclosure, and how social support from patients impacts FDR screening beliefs and practices. Sixteen colorectal cancer survivors and sixteen FDRs participated in the study.

While most patients said that they were willing to disclose their diagnosis to family members, many FDRs felt that the patients did so reluctantly. This study offers a unique perspective in that patient and FDR responses were compared to explore the experience from both viewpoints. Findings from this study have the potential to: 1) advance the lack of knowledge about the dynamics of CRC disclosure to FDRs in African

Americans, 2) identify appropriate provider recommendations for disease disclosure and communication of familial risk to FDRs, 3) inform the development of culturally relevant interventions related to CRC screening, 4) introduce the innovative use of the family secrets framework into public health research, and 5) ultimately narrow the CRC health disparity among African Americans, especially those with familial risk. This research provides valuable insight and information related to the challenges of CRC disease disclosure and the impact disclosure has on FDR screening and preventive health among African Americans.

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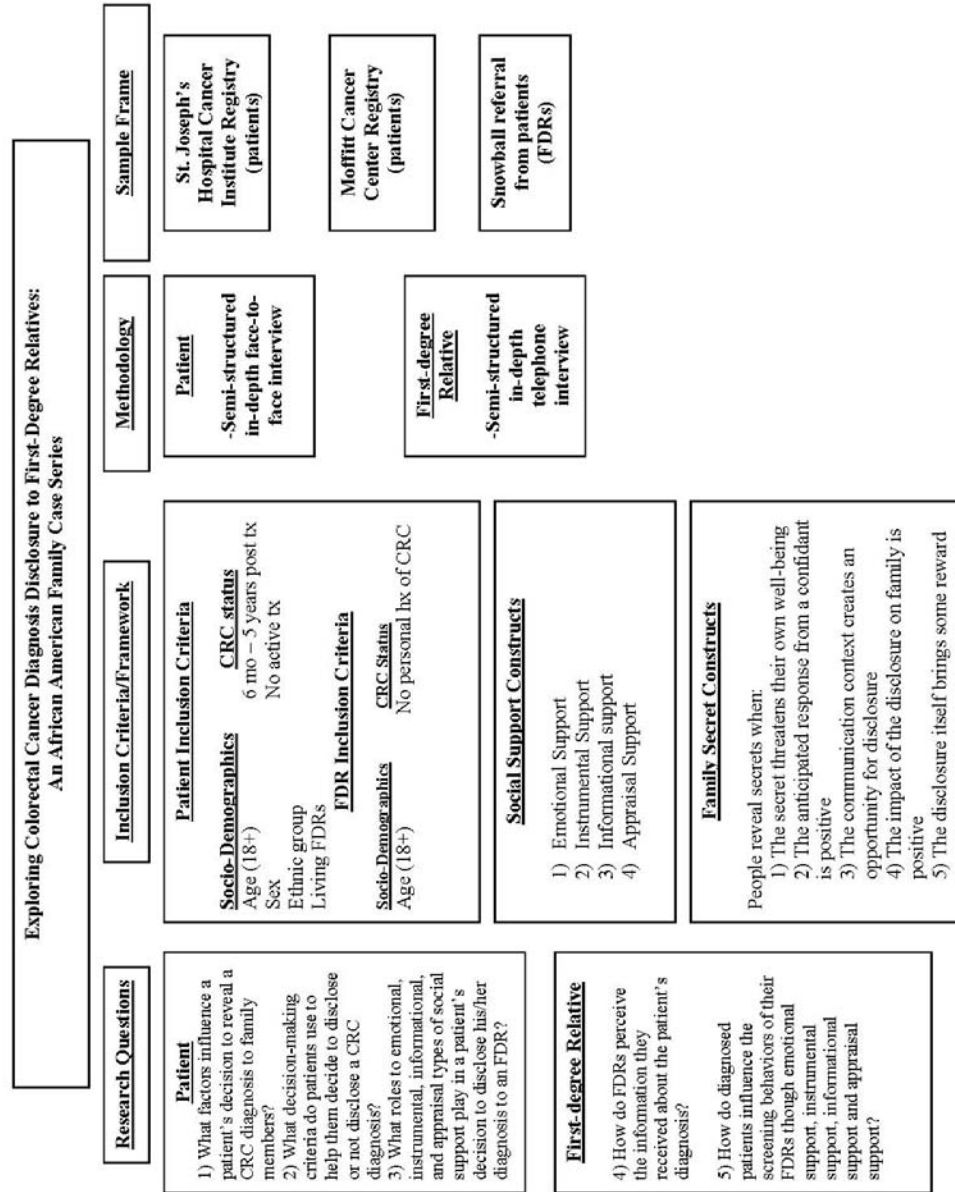
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Appendices

Appendix A: Concept Chart



Appendix B: IRB Approval Letters



DIVISION OF RESEARCH INTEGRITY AND COMPLIANCE

Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-5618

April 8, 2009

Clement Gwede, PhD
Moffitt
MDC 44/MRC-CANCONT
Attn: Lori Kirchhoff

RE: **Approved Modification Request**

IRB#: 106449 I

Title: *Understanding Patient Self-Disclosure of Colorectal Cancer Diagnosis and Screening Behaviors of First-Degree Relatives MCC# 15351*

Study Approval Period: 12/12/2008 to 12/11/2009

Dear Dr. Gwede:

On April 3, 2009 the Institutional Review Board (IRB) reviewed and **APPROVED** your Modification Request. The submitted request has been approved **from April 3, 2009 to 12/11/2009** for the following:

- 1. Change in research site: addition of St. Joseph's Hospital.**
- 2. Revised study instruments/materials: addition of sub-study interview guides for face to face and telephone interviews which will be audio taped. This sub-study is for a student's dissertation.**
- 3. Other: Revised protocol - Amendment 2, dated 2-23-09**
- 4. Change in consent process: Revision of Phase 1 and Phase 2 consent forms to include the new sub-study.**

New Expedited category 6 is added due to audio taping of participants.

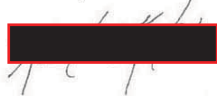
Please note, if applicable, the **enclosed informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on page one of the form.** Valid consent must be documented on a copy of the most recently IRB-approved consent form. Make copies from the enclosed original.

Please reference the above IRB protocol number in all correspondence to the IRB or the Division of Research Compliance. It is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB.

Appendix B: (Continued)

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-9343.

Sincerely,

A handwritten signature in black ink, appearing to read 'Krista Kutash', is written over a solid black rectangular redaction box.

Krista Kutash, Ph.D., Chairperson
USF Institutional Review Board

Enclosure: (If applicable) IRB-Approved, Stamped Informed Consent/Assent Documents(s)

Cc: Various Menzel/cd, USF IRB Support Staff

SB-MOD-Approved-0801

Appendix B: (Continued)



3001 W. Dr. Martin Luther King Jr. Blvd.
Tampa, FL 33607
T. 813.870.4000
www.stjosephstampa.com

St. Joseph's Hospital Institutional Review Board
Alison Calkins, MD., Co-Chairperson
Ian Matheson, MD., Co-Chairperson

MEMORANDUM: Changes in Procedure – Expedited



TO: **Clement K. Gwede, PhD.**
FROM: **Kristine Perez- IRB Specialist**
SUBJECT: **IRB File #2902**

PROTOCOL TITLE: *“Understanding Patient Self-Disclosure of Colorectal Cancer Diagnosis & Screening Behaviors of First-Degree Relatives” (Project #84-15049-02-03)*

The Co-Chairperson of Institutional Review Board (IRB) on this day **April 22, 2009**, has reviewed and approved the following under Expedited Review: *Modification, Revised Informed Consent Forms: Because patients (Phase One) reside in the local area, a face-to-face interview will be conducted and the open ended portion will be tape recorded. Also we extended the estimated time that it may take to complete the interview to accommodate the face-to-face interview time. A revised informed consent form is included.*

If the revised amendment consisted of a revised informed consent form(s), which has been updated to reflect the date of approval, then this is the only Consent Form(s) that should be used from this point forward. It must be signed by each subject prior to initiation of protocol. A signed copy should then be given to each of the subject participants.

The IRB has determined that the above-mentioned changes in procedure in this protocol **are at minimal risk**. This action will be reported at the **April 28 2009** IRB Meeting.



Alison Calkins, MD.
Ian Matheson, MD.
Co-Chairperson

St. Joseph's Institutional Review Board is governed by the regulations of the Food and Drug Administration as set forth in Title 21 of the Code of Federal Regulations Parts 30 and 36

Appendix C: Recruitment Letters



April 6, 2009

Dear _____:

Greetings! We are contacting you because you received primary surgery for colon or rectal cancer at Moffitt Cancer Center in the past five years. We would like to learn from you and your blood relatives the best ways to discuss colon cancer risk and check-ups. We expect to have 120 patients and 60 siblings or adult children take part in the study.

If you qualify and agree to participate in this study, we will ask you to participate in a face-to-face interview. During the interview you will answer general questions about health care, colon cancer and rectal cancer screening. The study staff will also ask you for the name, telephone number and mailing address of one or more of your adult blood relatives who already knows about your colon cancer diagnosis. This is important because we are interested in hearing the opinions of your family members in order to get a full picture of this important topic. Your relatives who agree to take part in the study will be asked similar questions over the telephone. If you decide not to give us a name of your relative that is fine, you may still participate in this study.

Once we begin, the discussion will last about 60–90 minutes. Before we begin, you will be given an informed consent form which describes your participation in more detail. You will be asked to read and sign the informed consent form before you can take part in the telephone interview. All of your responses will be kept strictly confidential and will not be shared with any one other than study staff. You will receive \$30 in appreciation for your time and effort for participating.

If you are not interested in participating in this study, please call 1-800-456-3434 ext. 6439 to leave a message and we will not contact you further. If we do not receive a phone message from you within the next week, we will call you to give you more information about the study, discuss your participation, and answer any questions you may have. If you agree to participate, we will schedule your telephone interview.

Thank you in advance for your help in this important work.

Sincerely,

Clement K. Gwede, Ph.D., M.P.H., R.N.
Principal Investigator

Sophie Dessureault, M.D., Ph.D., FRCS (C), FACS
Co-investigator

Appendix C: (Continued)



March 31, 2009

Dear _____:

Greetings! We are contacting you because you received primary surgery for colon or rectal cancer at St. Joseph's Cancer Institute in the past five years. Moffitt Cancer Center is partnering with St. Joseph's Hospital for a survey study. St. Joseph's Hospital sent you a letter introducing this study a few weeks ago. We would like to learn from you and your blood relatives the best ways to discuss colon cancer risk and check-ups. We expect to have 120 patients and 60 siblings or adult children take part in the study at both Moffitt Cancer Center and St. Joseph's Hospital Cancer Institute.

If you qualify and agree to participate in this study, we will ask you to participate in a face-to-face interview at a location of your choice. During the interview you will answer general questions about health care, colon cancer and rectal cancer screening. The study coordinator will also ask you for the name, telephone number and mailing address of one or more of your adult blood relatives who already knows about your colorectal cancer diagnosis. This is important because we are interested in hearing the opinions of your family members in order to get a full picture of this important topic. Your relatives who agree to take part in the study will be asked similar questions. If you decide not to give us a name of your relative that is fine, you may still participate in this study.

Once we begin, the discussion will last about 60–90 minutes. Before we begin, you will be given an informed consent form, which describes your participation in more detail. You will be asked to read and sign the informed consent form before you can take part in the face-to-face interview. All of your responses will be kept strictly confidential and will not be shared with anyone other than study staff. You will receive \$30 in appreciation for your time and effort for participating.

If you are not interested in participating in this study, please call 813-745-6439 and we will not contact you further. If we do not receive a phone message from you within the next week, we will call you to give you more information about the study, discuss your participation, and answer any questions you may have. If you agree to participate, we will schedule a telephone interview.

Thank you in advance for your help with this important work.

Sincerely,

Clement K. Gwede, PhD, MPH, RN
Principal Investigator

Kamilah B. Thomas, MPH, CHES
Study Coordinator

Appendix C: (Continued)



June 10, 2009

Dear _____:

Greetings! We are writing to you because we are contacting the relatives of patients who have received primary surgery for colon or rectal cancer at St. Joseph's Hospital in the past five years. Your mother, _____, gave us your contact information. We would like to learn from you and your relatives the best ways to discuss colon cancer risk and check-ups.

If you agree to participate in this study, we will ask you to participate in a telephone interview on a day and time that is best for you. During the telephone interview you will be asked questions about your thoughts about how your family member discussed their colon or rectal cancer diagnosis with you. There are no right or wrong answers, just different opinions. We want to hear different points of view. If you do not feel comfortable answering a question just let us know and you can skip it. We want to know your perspective as you see it.

Once we begin, the discussion will last about 30-35 minutes. Before we begin, you will be given an informed consent form, which describes your participation in more detail. You will be asked to read and sign the informed consent form before you can take part in the telephone interview. All of your responses will be kept strictly confidential and will not be shared with any one other than study staff. You will receive \$30 in appreciation for your time and effort for participating.

If you are not interested in participating in this study, please call 745- 6439 to leave a message and we will not contact you further. If we do not receive a phone message from you within the next week, we will call you to give you more information about the study, discuss your participation, and answer any questions you may have. If you agree to participate, we will schedule telephone interview.

Thank you in advance for your help in this important work.

Sincerely,

Kamilah B. Thomas
Research Coordinator

Clement K. Gwede, PhD, MPH, RN
Principal Investigator

Appendix D: Informed Consent

MCC# 15351

IRB# 106449

Subjects Name: _____

Adult Informed Consent and Authorization to Collect, Use and Share Your Health Information

University of South Florida/H. Lee Moffitt Cancer Center & Research Institute
Social and Behavioral Research

Information to Consider Before Taking Part in this Research Study

Researchers at H. Lee Moffitt Cancer Center & Research Institute study many topics. To do this, we need the help of people who agree to take part in a research study.

We are asking you to take part in a research study that is called: **Understanding patient self-disclosure of colorectal cancer diagnosis and screening behaviors of first-degree relatives (Phase 1: Patients)**

The person who is in charge of this research study is **Clement K. Gwede, PhD, MPH, RN**. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. The person explaining the research to you may be someone other than the Principal Investigator.

Other research personnel who you may be involved with include: Paul B. Jacobsen, PhD; Gwendolyn Quinn, PhD; David Shibata, MD; Sophie Dessureault, MD; Daohai Yu, PhD; Kamilah Thomas, MPH, CHES; and Will Tarver.

The research will be done at: **H. Lee Moffitt Cancer Center & Research Institute.**

Should you take part in this study?

This form tells you about this research study. This form explains:

- Why this study is being done.
- What will happen during this study and what you will need to do.
- Whether there is any chance you might experience potential benefits from being in the study.
- The risks of having problems because you are in this study.

Before you decide:

- Read this form.
- Have a friend or family member read it.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Talk it over with someone you trust.
- Find out what the study is about.
- You may have questions this form does not answer. You do not have to guess at things you don't understand. If you have questions ask the person in charge of the study or study staff as you go along. Ask them to explain things in a way you can understand.
- Take your time to think about it.

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13

IRB Approval	
FWA #0001469	
IRB Number:	106449 1
From	4-3-09
Thru	12-11-09

IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 1 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

It is up to you. If you choose to take part in this study, you will need to sign this consent form. If you do not want to take part in this study, you should **not sign the form.**

Why is this research being done?

The purpose of this study is to learn about your thoughts, opinions and experiences with telling your blood relatives (particularly your siblings and adult children) about your colon cancer or rectal cancer diagnosis.

Why are you being asked to take part?

You are being asked to participate because you have received primary surgery for colon or rectal cancer at Moffitt Cancer Center in the past five years. You have also indicated that you have at least 1 living adult sibling or adult biological child. We would like to learn from patients and their blood relatives the best ways to discuss colon cancer risk and check-ups.

What will happen during this study?

A member of the study staff will contact you by telephone on a day and time that is best for you. The study staff will talk to you about this study, determine if you qualify to take part in the study, and answer any questions you have. If you qualify and agree to take part in this study, we will ask you to sign and return a signed copy of this form in the postage paid preaddressed envelope provided.

Once you sign up for the study, you will answer questions in a face-to face interview (those living in the Tampa area) or telephone interview at a prearranged time convenient to you. During the face-to-face or telephone interview you will be asked questions about your thoughts about discussing your colorectal cancer diagnosis with your blood relatives (adult siblings or adult children). A portion of the interview will be recorded so that we don't miss anything. Afterwards, the recording will be transcribed and all names and identifying information will be removed. You can ask for the recorder to be turned off at any time. There are no right or wrong answers, just different opinions. We want to hear different points of view. If you don't feel comfortable answering a question, just let us know and you can skip it. We want to know your perspective as you see it.

During the second part of the interview, the study staff will ask you questions about yourself such as your age, race/ethnicity, marital status, education, employment, religion, income, and your thoughts about colon cancer. We will ask you questions from standard survey forms about your quality of life and how you feel in general. In addition, the study staff will gather information from your medical record chart at Moffitt Cancer Center about your colorectal cancer diagnosis and treatment. This information will include the date of your diagnosis, date of your surgery, cancer stage, and other cancer treatment you received.

The study staff will also ask you for the name, telephone number and mailing address of one or more of your adult blood relatives who already knows about your colon cancer diagnosis. This is important because we are interested in hearing the opinions of your family members in order to get a full picture of this important topic. Your relatives who agree to take part in the study will be asked similar questions. If you decide not to give us a name of your relative that is fine, you may still participate in this study.

Your participation in the interview will be one-time only.

We estimate that it will take about 60-90 minutes of your time to complete the telephone interview.

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 2 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

How many other people will take part?

We expect to have 120 patients and 60 siblings or adult children take part in the study.

What other choices do you have if you decide not to take part?

If you decide not to take part in this study, that is okay.

Instead of being in this research study you can choose not to participate.

Will you be paid for taking part in this study?

We will pay you for the time you volunteer while being in this study. You will receive \$30 for taking part in the interview.

What will it cost you to take part in this study?

It will not cost you anything to take part in the study.

What are the potential benefits if you take part in this study?

Although you may not experience any direct benefits, your participation may help future patients and their family members.

What are the risks if you take part in this study?

You are not likely to experience any risks by participating in this study.

Confidentiality of Information Used in the Study

The use and disclosure of your personal health information

We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your written authorization before we use or disclose your information for this study. This form provides that authorization and helps you understand how your information will be used or disclosed.

Research at the Moffitt Cancer Center is undertaken jointly with the University of South Florida or other persons or entities under an organized health care arrangement. By signing this form you are permitting the Moffitt Cancer Center to use personal health information collected about you for research purposes within its organized health care arrangements. You are also allowing the Moffitt Cancer Center to disclose your personal health information to outside organizations or individuals that participate in this study. We may publish what we find out from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Who will disclose, receive, and/or use your information?

Federal law says we must keep your study records private. We will keep the records of this study private by keeping them in a locked area of the H. Lee Moffitt Cancer Center & Research Institute. The following people and/or organization(s) will be allowed to disclose, use, and receive your information for the research purposes set forth in this form, but they may only use and disclose the information to the other parties on this list, to you or your personal representative, or as permitted by law:

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 3 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

- Every research site for this study, including the Moffitt Cancer Center, and each site's study team, research staff and medical staff;
- Every member of the Moffitt Cancer Center workforce who provides services in connection with this study;
- Any laboratories and other individuals and organizations that use your health information in connection with this study;
- Any sponsor of the study, including the following sponsors:
Department of Interdisciplinary Oncology – Research Account Funding at Moffitt Cancer Center
- Any federal, state or local governmental agency that regulates the study (such as the FDA and Florida Department of Health);
- The designated Protocol Review and Monitoring Committees, Institutional Review Boards, Privacy Boards, Data and Safety Monitoring Board and their related staff that have oversight responsibilities for this study;
- The National Cancer Institute in evaluating the ongoing research of the Moffitt Cancer Center as a Comprehensive Cancer Center.

The organizations and people listed above may employ or pay various consultants and companies to help them understand, analyze and conduct this study. All of these people may not be known now, but if you would like to have more specific information about this at any time during the study, you may ask the study doctor and your questions will be answered.

The Moffitt Cancer Center cannot guarantee the privacy of your information, or block further use or distribution, after the information has left the Moffitt Cancer Center. The sponsor of this study or others listed above may further disclose your information. If disclosed, the information may no longer be covered by federal privacy regulations.

What information will be used or disclosed?

By signing below, you authorize the use and disclosure of your entire study record and any medical or other records held by the Moffitt Cancer Center, including, but not limited to, HIV/AIDS, mental health, substance abuse or genetic information, except for information that you expressly exclude below. The purpose for the uses and disclosures you are authorizing is to conduct the study explained to you during the informed consent and research authorization process and to ensure that the information relating to that study is available to all parties who may need it for research purposes.

☐ Exclude the information expressly listed below (if blank, then no information excluded):

By signing this form, you authorize the use and/or disclosure of your protected health information described above. Your information may also be used as necessary for your research-related treatment,

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 4 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

to collect payment for your research-related treatment (when applicable), and to run the business operations of the Moffitt Cancer Center. Your authorization to use your health information will never expire unless and until you expressly revoke it in writing.

What happens if you decide not to take part in this study?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study to please the study doctor or the research staff.

If you decide not to take part:

- You won't be in trouble or lose any rights you normally have.
- You will still get the same services you would normally have.

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call Dr. Clement Gwede at (813) 745-3052.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.

If you experience an adverse event or unanticipated problem call Dr. Clement Gwede at (813) 745-3052.

Statement of Participation in Research

It is up to you to decide whether you want to take part in this study. If you want to take part, please read the statements below and sign the form if the statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent / Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 5 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

- How the information collected about the person will be used.

I also certify that he or she does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language that was used to explain this research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 1: patients)
Page 6 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

Adult Informed Consent and Authorization to Collect, Use and Share Your Health Information

University of South Florida/H. Lee Moffitt Cancer Center & Research Institute
Social and Behavioral Research

Information to Consider Before Taking Part in this Research Study

Researchers at H. Lee Moffitt Cancer Center & Research Institute study many topics. To do this, we need the help of people who agree to take part in a research study.

We are asking you to take part in a research study that is called: **Understanding patient self-disclosure of colorectal cancer diagnosis and screening behaviors of first-degree relatives (Phase 2: Relatives)**

The person who is in charge of this research study is **Clement K. Gwede, PhD, MPH, RN**. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. The person explaining the research to you may be someone other than the Principal Investigator.

Other research personnel who you may be involved with include: Paul B. Jacobsen, PhD; Gwendolyn Quinn, PhD; David Shibata, MD; Sophie Dessurcault, MD; Daohai Yu, PhD; Kamilah Thomas, MPH, CHES; and Will Tarver.

The research will be done at: **H. Lee Moffitt Cancer Center & Research Institute.**

Should you take part in this study?

This form tells you about this research study. This form explains:

- Why this study is being done.
- What will happen during this study and what you will need to do.
- Whether there is any chance you might experience potential benefits from being in the study.
- The risks of having problems because you are in this study.

Before you decide:

- Read this form.
- Have a friend or family member read it.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Talk it over with someone you trust.
- Find out what the study is about.
- You may have questions this form does not answer. You do not have to guess at things you don't understand. If you have questions ask the person in charge of the study or study staff as you go along. Ask them to explain things in a way you can understand.
- Take your time to think about it.

IRB Number: 106449

IRB SBR ICF and Res Auth Rev 2006-11-13

IRB Approval FWA #0001609	
IRB Number:	1064493
From:	4-3-09
Thru:	12-11-09

IRB Consent Rev. Date: 03/30/2009

Informed Consent Rev #3 (phase 2: relatives)

Page 1 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

It is up to you. If you choose to take part in this study, you will need to sign this consent form. If you do not want to take part in this study, you should **not sign the form.**

Why is this research being done?

The purpose of this study is to learn about your thoughts, opinions and experiences with having your blood relative (particularly your parent or sibling) tell you about their colon cancer or rectal cancer diagnosis.

Why are you being asked to take part?

You are being asked to participate because your parent or sibling received primary surgery for colon or rectal cancer at Moffitt Cancer Center in the past five years. Your family member gave us your contact information. We would like to learn from patients and their blood relatives the best ways to discuss colon cancer risk and check-ups.

What will happen during this study?

A member of the study staff will contact you by telephone on a day and time that is best for you. The study staff will talk to you about this study, determine if you qualify to take part in the study, and answer any questions you have. If you qualify and agree to take part in this study, we will ask you to sign and return a signed copy of this form in the postage paid preaddressed envelope provided.

Once you sign up for the study, you will answer questions in a telephone interview at a prearranged time convenient to you. During the telephone interview you will be asked questions about your thoughts about how your family member discussed their colon or rectal cancer diagnosis with you. There are no right or wrong answers, just different opinions. We want to hear different points of view. A portion of the interview will be recorded so that we don't miss anything. Afterwards, the recording will be transcribed and all names and identifying information will be removed. You can ask for the recorder to be turned off at any time. If you don't feel comfortable answering a question, just let us know and you can skip it. We want to know your perspective as you see it.

During the second part of the interview, the study staff will ask you questions about yourself such as your age, race/ethnicity, marital status, education, employment, religion, income, and your thoughts about colon cancer. We will ask you questions from standard survey forms about your quality of life and how you feel in general.

We are interested in hearing your opinions in order to get a full picture of this important topic. Your relative who recommends you for this study will also be asked similar questions.

Your participation in the interview will be one-time only.

We estimate that it will take about 60-90 minutes of your time to complete the telephone interview.

How many other people will take part?

We expect to have 120 patients and 60 siblings or adult children take part in the study.

What other choices do you have if you decide not to take part?

If you decide not to take part in this study, that is okay.

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 2: relatives)
Page 2 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

Instead of being in this research study you can choose not to participate.

Will you be paid for taking part in this study?

We will pay you for the time you volunteer while being in this study. You will receive \$30 for taking part in the interview.

What will it cost you to take part in this study?

It will not cost you anything to take part in the study.

What are the potential benefits if you take part in this study?

Although you may not experience any direct benefits, your participation may help future patients and their family members.

What are the risks if you take part in this study?

You are not likely to experience any risks by participating in this study.

Confidentiality of Information Used in the Study

The use and disclosure of your personal health information

We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your written authorization before we use or disclose your information for this study. This form provides that authorization and helps you understand how your information will be used or disclosed.

Research at the Moffitt Cancer Center is undertaken jointly with the University of South Florida or other persons or entities under an organized health care arrangement. By signing this form you are permitting the Moffitt Cancer Center to use personal health information collected about you for research purposes within its organized health care arrangements. You are also allowing the Moffitt Cancer Center to disclose your personal health information to outside organizations or individuals that participate in this study. We may publish what we find out from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Who will disclose, receive, and/or use your information?

Federal law says we must keep your study records private. We will keep the records of this study private by keeping them in a locked area of the H. Lee Moffitt Cancer Center & Research Institute. The following people and/or organization(s) will be allowed to disclose, use, and receive your information for the research purposes set forth in this form, but they may only use and disclose the information to the other parties on this list, to you or your personal representative, or as permitted by law:

- Every research site for this study, including the Moffitt Cancer Center, and each site's study team, research staff and medical staff;
- Every member of the Moffitt Cancer Center workforce who provides services in connection with this study;

IRB Number:106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date:03/30/2009
Informed Consent Rev #3 (phase 2: relatives)
Page 3 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

- Any laboratories and other individuals and organizations that use your health information in connection with this study;
- Any sponsor of the study, including the following sponsors:
Department of Interdisciplinary Oncology – Research Account Funding at Moffitt Cancer Center
- Any federal, state or local governmental agency that regulates the study (such as the FDA and Florida Department of Health);
- The designated Protocol Review and Monitoring Committees, Institutional Review Boards, Privacy Boards, Data and Safety Monitoring Board and their related staff that have oversight responsibilities for this study;
- The National Cancer Institute in evaluating the ongoing research of the Moffitt Cancer Center as a Comprehensive Cancer Center.

The organizations and people listed above may employ or pay various consultants and companies to help them understand, analyze and conduct this study. All of these people may not be known now, but if you would like to have more specific information about this at any time during the study, you may ask the study doctor and your questions will be answered.

The Moffitt Cancer Center cannot guarantee the privacy of your information, or block further use or distribution, after the information has left the Moffitt Cancer Center. The sponsor of this study or others listed above may further disclose your information. If disclosed, the information may no longer be covered by federal privacy regulations.

What information will be used or disclosed?

By signing below, you authorize the use and disclosure of your entire study record and any medical or other records held by the Moffitt Cancer Center, including, but not limited to, HIV/AIDS, mental health, substance abuse or genetic information, except for information that you expressly exclude below. The purpose for the uses and disclosures you are authorizing is to conduct the study explained to you during the informed consent and research authorization process and to ensure that the information relating to that study is available to all parties who may need it for research purposes.

☐ Exclude the information expressly listed below (if blank, then no information excluded):

By signing this form, you authorize the use and/or disclosure of your protected health information described above. Your information may also be used as necessary for your research-related treatment, to collect payment for your research-related treatment (when applicable), and to run the business operations of the Moffitt Cancer Center. Your authorization to use your health information will never expire unless and until you expressly revoke it in writing.

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 2: relatives)
Page 4 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____

What happens if you decide not to take part in this study?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study to please the study doctor or the research staff.

If you decide not to take part:

- You won't be in trouble or lose any rights you normally have.
- You will still get the same services you would normally have.

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call Dr. Clement Gwede at (813) 745-3052.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, call the Division of Research Integrity and Compliance of the University of South Florida at (813) 974-9343.

If you experience an adverse event or unanticipated problem call Dr. Clement Gwede at (813) 745-3052.

Statement of Participation in Research

It is up to you to decide whether you want to take part in this study. If you want to take part, please read the statements below and sign the form if the statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent / Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.
- How the information collected about the person will be used.

I also certify that he or she does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language that was used to explain this

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 2: relatives)
Page 5 of 6

Appendix D: (Continued)

MCC# 15351

IRB# 106449

Subjects Name: _____
research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

IRB Number: 106449
IRB SBR ICF and Res Auth Rev 2006-11-13



IRB Consent Rev. Date: 03/30/2009
Informed Consent Rev #3 (phase 2: relatives)
Page 6 of 6

Appendix D: (Continued)

We are asking you to take part in a research study that is called: **Understanding patient self-disclosure of colorectal cancer diagnosis and screening behaviors of first-degree relatives (Phase 1: Patients)**

The person who is in charge of this research study is **Clement K. Gwede, PhD, MPH, RN**. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. The person explaining the research to you may be someone other than the Principal Investigator.

The research coordinator that you will be involved with is: Kamilah B. Thomas, MPH, CHES

The research is sponsored by: **H. Lee Moffitt Cancer Center & Research Institute**.

Protocol# 2902

Should you take part in this study?

This form tells you about this research study. This form explains:

- Why this study is being done.
- What will happen during this study and what you will need to do.
- Whether there is any chance you might experience potential benefits from being in the study.
- The risks of having problems because you are in this study.

Before you decide:

- Read this form.
- Have a friend or family member read it.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Talk it over with someone you trust.
- Find out what the study is about.
- You may have questions this form does not answer. You do not have to guess at things you don't understand. If you have questions ask the person in charge of the study or study staff as you go along. Ask them to explain things in a way you can understand.
- Take your time to think about it.

It is up to you. If you choose to take part in this study, you will need to sign this consent form. If you do not want to take part in this study, you should not sign the form.

Why is this research being done?

The purpose of this study is to learn about your thoughts, opinions and experiences with telling your blood relatives (particularly your siblings and adult children) about your colon cancer or rectal cancer diagnosis.

Why are you being asked to take part?

You are being asked to participate because you have received primary surgery for colon or rectal cancer at St. Joseph's Hospital in the past five years. You have also indicated that you have at least 1 living

Appendix D: (Continued)

adult sibling or adult biological child. We would like to learn from patients and their blood relatives the best ways to discuss colon cancer risk and check-ups.

What will happen during this study?

A member of the study staff will contact you by telephone on a day and time that is best for you. The study staff will talk to you about this study, determine if you qualify to take part in the study, and answer any questions you have. If you qualify and agree to take part in this study, we will ask you to sign and return a signed copy of this form in the postage paid preaddressed envelope provided.

Once you sign up for the study, you will answer questions in a face-to face interview (those living in the Tampa area) or telephone interview at a prearranged time convenient to you. During the face-to-face or telephone interview you will be asked questions about your thoughts about discussing your colorectal cancer diagnosis with your blood relatives (adult siblings or adult children). A portion of the interview will be recorded so that we don't miss anything. Afterwards, the recording will be transcribed and all names and identifying information will be removed. You can ask for the recorder to be turned off at any time. There are no right or wrong answers, just different opinions. We want to hear different points of view. If you don't feel comfortable answering a question, just let us know and you can skip it. We want to know your perspective as you see it.

During the second part of the interview, the study staff will ask you questions about yourself such as your age, race/ethnicity, marital status, education, employment, religion, income, and your thoughts about colon cancer. We will ask you questions from standard survey forms about your quality of life and how you feel in general.

The study staff will also ask you for the name, telephone number and mailing address of one or more of your adult blood relatives who already knows about your colon cancer diagnosis. This is important because we are interested in hearing the opinions of your family members in order to get a full picture of this important topic. Your relatives who agree to take part in the study will be asked similar questions. If you decide not to give us a name of your relative that is fine, you may still participate in this study.

Your participation in the interview will be one-time only.

We estimate that it will take about 60-90 minutes of your time to complete the telephone interview.

How many other people will take part?

We expect to have 120 patients and 60 siblings or adult children take part in the study.

What other choices do you have if you decide not to take part?

If you decide not to take part in this study, that is okay.

Instead of being in this research study you can choose not to participate.

Will you be paid for taking part in this study?

We will pay you for the time you volunteer while being in this study. You will receive \$30 for taking part in the interview.

What will it cost you to take part in this study?

Appendix D: (Continued)

It will not cost you anything to take part in the study.

What are the potential benefits if you take part in this study?

Although you may not experience any direct benefits, your participation may help future patients and their family members.

What are the risks if you take part in this study?

You are not likely to experience any risks by participating in this study.

What happens if I get injured in the study?

You are not likely to experience injury from participation in this study. However, if injury occurs, treatment will, in most cases, be available. Such treatment will be at your expense or the expense of your insurance carrier. In the event of physical or psychological injury, St. Joseph's Hospital will not provide reimbursement for such injuries or any other compensation (such as for lost wages). St. Joseph's Hospital will provide the medical and ancillary services ordered by your doctor at the established charges for those services. No money will be provided by Moffitt Cancer Center or the physicians as compensation for a trial-related injury. You are not waiving any legal rights. You are not releasing the hospital or physicians from liability for negligence unrelated to the nature and risk of the treatment.

Confidentiality of Information Used in the Study

The use and disclosure of your personal health information

We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your written authorization before we use or disclose your information for this study. This form provides that authorization and helps you understand how your information will be used or disclosed.

Research at St. Joseph's Hospital is undertaken jointly with other persons or entities under an organized health care arrangement. By signing this form you are permitting St. Joseph's Hospital to use personal health information collected about you for research purposes within its organized health care arrangements. You are also allowing St. Joseph's Hospital to disclose your personal health information to outside organizations or individuals that participate in this study. We may publish what we find out from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Who will have access to information about my participation in the study?

Information about your participation in this study will be kept confidential; however, representatives of the Food and Drug Administration, Moffitt Cancer Center, and the St. Joseph's Hospital institutional Board and may inspect your records for purposes of compliance, quality assurance and data analysis. Disclosure of information may also be required by law. Therefore, absolute confidentiality cannot be guaranteed.

The results of the research study may be presented at meetings or in publications; however your identity will remain confidential.

What information will be used or disclosed?

Appendix D: (Continued)

By signing below, you authorize the use and disclosure of your entire study record and any medical or other records held by St. Joseph's Hospital, including, but not limited to, HIV/AIDS, mental health, substance abuse or genetic information, except for information that you expressly exclude below. The purpose for the uses and disclosures you are authorizing is to conduct the study explained to you during the informed consent and research authorization process and to ensure that the information relating to that study is available to all parties who may need it for research purposes.

☐ Exclude the information expressly listed below (if blank, then no information excluded):

By signing this form, you authorize the use and/or disclosure of your protected health information described above. Your authorization to use your health information will never expire unless and until you expressly revoke it in writing.

What happens if you decide not to take part in this study?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study to please the study doctor or the research staff.

If you decide not to take part:

- You won't be in trouble or lose any rights you normally have.
- You will still get the same services you would normally have.

You can decide after signing this informed consent document that you no longer want to take part in this study. If you decide you want to stop taking part in the study, contact Kamilah B. Thomas, the research coordinator as soon as you can at (813) 745-6439.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, you may contact the Coordinator of the Institutional Review Board at (813) 870-4968 for questions about your rights as a research subject.

- We will tell you how to stop safely. We will tell you if there are any dangers if you stop suddenly.
- If you decide to stop, you can go on getting your regular care.

Even if you want to stay in the study, there may be reasons we will need to take you out of it. You may be taken out of this study if:

- We find out it is not safe for you to stay in the study. For example, your health may get worse.
- You are not coming for your study visits when scheduled.

Appendix D: (Continued)

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call Dr. Clement Gwede at (813) 745-3052.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, you may contact the Coordinator of the Institutional Review Board at (813) 870-4968 for questions about your rights as a research subject.

If you experience an adverse event or unanticipated problem call Dr. Clement Gwede at (813) 745-3052.

Statement of Participation in Research

It is up to you to decide whether you want to take part in this study. If you want to take part, please read the statements below and sign the form if the statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a signed and dated copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Approved By The St. Joseph's Hospital
Institutional Review Board
FWA 00008065

IRB File #: 2902

Date Reviewed And Approved: 4/28/09

Expiration Date: _____

Co-Chairperson: _____

Informed Consent (phase 1: patients)
Page 5 of 6

Appendix D: (Continued)

Statement of Person Obtaining Informed Consent / Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.
- How the information collected about the person will be used.

I also certify that he or she does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language that was used to explain this research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

Approved By The St. Joseph's Hospital
Institutional Review Board
PWA 00006065

IRB File #: 2902

Date Reviewed And Approved: 4/28/09

Expiration Date: _____

Co-Chairperson: _____

Informed Consent (phase 1: patients)
Page 6 of 6

Appendix D: (Continued)

We are asking you to take part in a research study that is called: **Understanding patient self-disclosure of colorectal cancer diagnosis and screening behaviors of first-degree relatives (Phase 2: Relatives)**

The person who is in charge of this research study is **Clement K. Gwede, PhD, MPH, RN**. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. The person explaining the research to you may be someone other than the Principal Investigator.

The research coordinator that you will be involved with is: Kamilah B. Thomas, MPH, CHES

The research is being sponsored by: **H. Lee Moffitt Cancer Center & Research Institute**.

Protocol# 2902

Should you take part in this study?

This form tells you about this research study. This form explains:

- Why this study is being done.
- What will happen during this study and what you will need to do.
- Whether there is any chance you might experience potential benefits from being in the study.
- The risks of having problems because you are in this study.

Before you decide:

- Read this form.
- Have a friend or family member read it.
- Talk about this study with the person in charge of the study or the person explaining the study. You can have someone with you when you talk about the study.
- Talk it over with someone you trust.
- Find out what the study is about.
- You may have questions this form does not answer. You do not have to guess at things you don't understand. If you have questions ask the person in charge of the study or study staff as you go along. Ask them to explain things in a way you can understand.
- Take your time to think about it.

It is up to you. If you choose to take part in this study, you will need to sign this consent form. If you do not want to take part in this study, you should not sign the form.

Why is this research being done?

The purpose of this study is to learn about your thoughts, opinions and experiences with having your blood relative (particularly your parent or sibling) tell you about their colon cancer or rectal cancer diagnosis.

Why are you being asked to take part?

You are being asked to participate because your parent or sibling received primary surgery for colon or rectal cancer at St. Joseph's Hospital in the past five years. Your family member gave us your contact

Appendix D: (Continued)

information. We would like to learn from patients and their blood relatives the best ways to discuss colon cancer risk and check-ups.

What will happen during this study?

A member of the study staff will contact you by telephone on a day and time that is best for you. The study staff will talk to you about this study, determine if you qualify to take part in the study, and answer any questions you have. If you qualify and agree to take part in this study, we will ask you to sign and return a signed copy of this form in the postage paid preaddressed envelop provided.

Once you sign up for the study, you will answer questions in a telephone interview at a prearranged time convenient to you. During the telephone interview you will be asked questions about your thoughts about how your family member discussed their colon or rectal cancer diagnosis with you. There are no right or wrong answers, just different opinions. We want to hear different points of view. A portion of the interview will be recorded so that we don't miss anything. Afterwards, the recording will be transcribed and all names and identifying information will be removed. You can ask for the recorder to be turned off at any time. If you don't feel comfortable answering a question, just let us know and you can skip it. We want to know your perspective as you see it.

During the second part of the interview, the study staff will ask you questions about yourself such as your age, race/ethnicity, marital status, education, employment, religion, income, and your thoughts about colon cancer. We will ask you questions from standard survey forms about your quality of life and how you feel in general.

We are interested in hearing your opinions in order to get a full picture of this important topic. Your relative who recommend you for this study will also be asked similar questions.

Your participation in the interview will be one-time only.

We estimate that it will take about 60-90 minutes of your time to complete the telephone interview.

How many other people will take part?

We expect to have 120 patients and 60 siblings or adult children take part in the study.

What other choices do you have if you decide not to take part?

If you decide not to take part in this study, that is okay.

Instead of being in this research study you can choose not to participate.

Will you be paid for taking part in this study?

We will pay you for the time you volunteer while being in this study. You will receive \$30 for taking part in the interview.

What will it cost you to take part in this study?

It will not cost you anything to take part in the study.

What are the potential benefits if you take part in this study?

Appendix D: (Continued)

Although you may not experience any direct benefits, your participation may help future patients and their family members.

What are the risks if you take part in this study?

You are not likely to experience injury from participation in this study. However, if injury occurs, treatment will, in most cases, be available. Such treatment will be at your expense or the expense of your insurance carrier. In the event of physical or psychological injury, St. Joseph's Hospital will not provide reimbursement for such injuries or any other compensation (such as for lost wages). St. Joseph's Hospital will provide the medical and ancillary services ordered by your doctor at the established charges for those services. No money will be provided by Moffitt Cancer Center or the physicians as compensation for a trial-related injury. You are not waiving any legal rights. You are not releasing the hospital or physicians from liability for negligence unrelated to the nature and risk of the treatment.

Confidentiality of Information Used in the Study

The use and disclosure of your personal health information

We understand that information about you and your health is personal, and we are committed to protecting the privacy of that information. Because of this commitment, we must obtain your written authorization before we use or disclose your information for this study. This form provides that authorization and helps you understand how your information will be used or disclosed.

Research at St. Joseph's Hospital is undertaken jointly with other persons or entities under an organized health care arrangement. By signing this form you are permitting St. Joseph's Hospital to use personal health information collected about you for research purposes within its organized health care arrangements. You are also allowing St. Joseph's Hospital to disclose your personal health information to outside organizations or individuals that participate in this study. We may publish what we find out from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are.

Who will have access to information about my participation in the study?

Information about your participation in this study will be kept confidential; however, representatives of the Food and Drug Administration, Moffitt Cancer Center, and the St. Joseph's Hospital institutional Board and may inspect your records for purposes of compliance, quality assurance and data analysis. Disclosure of information may also be required by law. Therefore, absolute confidentiality cannot be guaranteed.

The results of the research study may be presented at meetings or in publications; however your identity will remain confidential.

What information will be used or disclosed?

By signing below, you authorize the use and disclosure of your entire study record. The purpose for the uses and disclosures you are authorizing is to conduct the study explained to you during the informed consent and research authorization process and to ensure that the information relating to that study is available to all parties who may need it for research purposes.

Appendix D: (Continued)

What happens if you decide not to take part in this study?

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study to please the study doctor or the research staff.

If you decide not to take part:

- You won't be in trouble or lose any rights you normally have.
- You will still get the same services you would normally have.

You can decide after signing this informed consent document that you no longer want to take part in this study. If you decide you want to stop taking part in the study, tell the study staff as soon as you can.

- We will tell you how to stop safely. We will tell you if there are any dangers if you stop suddenly.
- If you decide to stop, you can go on getting your regular care.

Even if you want to stay in the study, there may be reasons we will need to take you out of it. You may be taken out of this study if:

- We find out it is not safe for you to stay in the study. For example, your health may get worse.
- You are not coming for your study visits when scheduled.

You can get the answers to your questions, concerns, or complaints.

If you have any questions, concerns or complaints about this study, call Dr. Clement Gwede at (813) 745-3052.

If you have questions about your rights, general questions, complaints, or issues as a person taking part in this study, call the Coordinator of the Institutional Review Board at (813) 870-4968

If you experience an adverse event or unanticipated problem call Dr. Clement Gwede at (813) 745-3052.

Statement of Participation in Research

It is up to you to decide whether you want to take part in this study. If you want to take part, please read the statements below and sign the form if the statements are true.

I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a signed and dated copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Appendix D: (Continued)

Statement of Person Obtaining Informed Consent / Research Authorization

I have carefully explained to the person taking part in the study what he or she can expect.

I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about.
- What procedures/interventions/investigational drugs or devices will be used.
- What the potential benefits might be.
- What the known risks might be.
- How the information collected about the person will be used.

I also certify that he or she does not have any problems that could make it hard to understand what it means to take part in this research. This person speaks the language that was used to explain this research.

This person reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her.

This person does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give informed consent.

This person is not taking drugs that may cloud their judgment or make it hard to understand what is being explained and can, therefore, give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

Approved By The St. Joseph's Hospital
Institutional Review Board
FWA 00006065

IRB File #: 2902

Date Reviewed And Approved: 4/28/09

Expiration Date: _____

Co-Chair/person: _____

Appendix E: Interview Guides

Patient Interview Guide

I want to thank you for taking the time to meet with me today. My name is Kamilah and I would like to talk to you about how you decided who to tell about your colorectal cancer diagnosis and how the process went for you. Your insight and opinions on this subject will be used to help other people who have to face similar decisions after learning they have colorectal cancer. There are no right or wrong answers, so please say what's on your mind and what you think.

The portion of the interview should take about half an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments. All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time.

I hope you will feel comfortable here today and share all of your opinions, both positive and negative. We value all your ideas. Do you have any questions about this study or today's interview?

Okay, let's begin.

- 1) Can you think back to when you were first diagnosed with Colorectal Cancer and tell me about your experience?
- 2) When you first learned about your Colorectal Cancer diagnosis what were the first 3 things that came to mind?
- 3) Which first degree relatives (parents, siblings, children) did you decide to tell? (make list)
- 4) What was the decision of who to tell like for you? (Probe: What was hard, easy? What factors did you consider?)
- 5) What was the major reason you decided to tell ____?
- 6) How did it go when you told him/her?
- 7) Think back to when you revealed your diagnosis, when did you feel it was an appropriate time to reveal your diagnosis? What type of setting was helpful? (Probe: Were you at home? Was it over the phone? Was it quiet?)

Appendix E: (Continued)

- 8) How did you feel when you revealed your Colorectal Cancer diagnosis?
- 9) How did you expect people to respond? What did you hope would happen (Probe: Did you want them to show that they loved you, cared for you, in what way?; Did you hope they would take you to appointments, help you cook or clean?; Did you want them to find out more about CRC or get more information for you?; Did you want them to tell you that you were handling the news of your illness well or that it wasn't your fault)
- 10) How did they actually respond or react to the news? What did s/he say? What did s/he do?
- 11) How were your family member's responses like each other and how were they different from each other?
- 12) Now I want to ask you about after your treatment. Since your treatment ended, how has your family responded to you?
- 13) How do you feel now about your decision to share your diagnosis with him/her? (Probe: Are you glad/sorry you shared it with them? Why?)
- 14) Were there any relatives that you didn't tell about your colorectal cancer diagnosis?
- 15) What made you not tell those relatives? Do you wish you had told them? Why do you say that?
- 16) As you think back about all of the experiences that we have discussed today, what type of effect do you think disclosing your Colorectal Cancer Diagnosis has had on your relatives? (Probe: What about their decisions to get screened?)
- 17) Do you know if any of your relatives got screened after you told them? (Probe: Who? What did they tell you about their decision to be screened?)
- 18) How did discussing your diagnosis of Colorectal Cancer compare to other secrets or private information that you had to share with family members in the past?
- 19) When you think of Colorectal Cancer now, what 3 things come to mind?

That was a great conversation. I am really thankful for all your input and honesty. You were very helpful. Do you have any questions for me? Thank you for your time. If any questions come up, you may contact me at the number or email on your fact sheet.

Appendix E: (Continued)

FDR Telephone Interview Guide

I want to thank you for allowing me to call you today. My name is Kamilah and I would like to talk to you about your experience with learning about your family member's colorectal cancer diagnosis and how that process went for you. Your insight and opinions on this subject will be used to help other people who have to face similar situations after learning about their family member's diagnosis. There are no right or wrong answers, so please say what's on your mind and what you think.

This portion of the interview should take less than an hour. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments. All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time.

I hope you will feel comfortable here today and share all of your opinions, both positive and negative. We value all your ideas. Do you have any questions about this study or today's interview?

Okay, let's begin.

1. Can you tell me about when you first learned that _____ had Colorectal Cancer?
2. When you first learned about your relative's Colorectal Cancer diagnosis what were the first 3 things that came to mind?
3. Who told you that s/he had Colorectal Cancer?
4. Why do you think s/he told you? (Probe: Did they worry about survival or recovery?; Was the news too stressful to not share?)
5. Was the environment good for that type of conversation? What was good or bad about the time and place that you were told?
6. How did you react when you first learned about the Colorectal Cancer diagnosis? (Probe: Were you empathetic?; Did you offer to do anything to help (like cooking, cleaning)?; Did you offer advice?; Did you tell them that they handling the news of cancer in a good way?)
7. What impact did this news have on you? Did you do anything differently?

Appendix E: (Continued)

8. What do you think your family member expected from you by telling you about their diagnosis?
9. Have you personally been screened for CRC? Was that before or after learning about ____'s Colorectal Cancer diagnosis? ; How long after? What made you go at that time?
10. What impact did the diagnosed patient have on your decision (or not) to get screened?
11. Did they do anything to encourage you to be screened? (Probe: Did they care if you were screened? Did they give you information on where to get screened? Did they offer to take you to get screened? Did they make you feel good about being screened?)
12. When you think of CRC now, what comes to mind?

That was a great conversation. I am really thankful for all your input and honesty. You were very helpful. Do you have any questions for me? Thank you for your time. If any questions come up, you may contact me at the number or email on your consent form.

Appendix F: Thank You Note



May 7, 2009

Dear _____,

Thank you for participating in the *Discussing Colorectal Cancer Risk with Family Members* research study. We have learned a lot from your opinions and experiences and understand that your time is important. Please find a \$30 money order enclosed to thank you for your assistance.

On behalf of the entire research team, thank you again for contributing to the prevention and cure of cancer. Please let me know if you have any questions or concerns.

Sincerely,

Kamilah B. Thomas
Research Coordinator
Moffitt Cancer Center & Research Institute
813-745-6439 (office)
813-745-6525 (fax)
kamilah.thomas@moffitt.org (email)

About the Author

Kamilah B. Thomas, daughter of Aldwyn and Claudette Thomas was born on October 19, 1978. In 1997, she graduated with honors from Hallandale High School located in Hallandale Beach, FL. She attended the University of Florida in Gainesville, Florida where she graduated cum laude in 2001 with a Bachelor of Health Science Degree. That same year she began graduate school at the University of North Carolina at Chapel Hill and graduated in 2003 with a Master of Public Health (MPH) Degree in Health Behavior and Health Education. Upon completion of her MPH, she became an Association for Schools of Public Health (ASPH) Environmental Health Education Fellow. As an ASPH fellow, she worked at the Centers for Disease Control and Prevention in Atlanta, GA in the Lead Poisoning Prevention Branch. In 2005, she was admitted into the Doctor of Philosophy in Public Health program at the University of South Florida (USF) in Tampa, Florida. While at USF, she studied in the Department of Community and Family Health in the College of Public Health and worked as a Research Coordinator at the H. Lee Moffitt Cancer Center and Research Institute, a National Cancer Institute Comprehensive Cancer Center.